

# CHILDREN'S MENTAL HEALTH CRISIS SERVICES PLANNING GRANT

### MHDS 17-005

# **FINAL REPORT: JULY 2017**

# **Submitted by:**

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#### **EXECUTIVE SUMMARY**

The purpose of this grant was to develop a Children's Mental Health Crisis and Stabilization service plan for the seven county North Central Iowa area. Francis Lauer Youth Services-A YSS Organization, was the lead for this planning project. The collaborative Planning Group, composed of eleven representatives from a variety of community sectors, met twelve times from October 2016 through June 2017 to develop the plan. Subcommittees also met during this time and consultation was provided by other partners and stakeholders. The Center for Social and Behavioral Research at the University of Northern Iowa (UNI) was contracted to conduct a needs assessment for the plan and to assist in the planning group in other research and development activity.

In addition to gathering archival data, the UNI research team conducted interviews with stakeholders, focus groups with parents and youth, and telephone interviews with parents. Some key findings from the needs assessment research are:

- The number of young children with serious mental health conditions has increased in recent years. Mental health challenges (their own or others') are a central part of life for many youth. Family structure and circumstances are viewed as playing a major role in children's mental health. Stigma is a significant concern among parents. Youth express some ambivalent attitudes towards mental health, but stigma is still a barrier to help-seeking.
- More accessible mental health care is needed for children. Scarcity of services/providers, long waiting times, transportation, and cost/insurance coverage barriers are significant obstacles to accessing mental health care for children. The lack of providers who attend to and screen young children limits treatment options.
- There is significant need for better collaboration and coordination among providers and agencies and for greater coordination and communication across sectors. There is a lack of comprehensive training on children's mental health. Schools play a central role in identifying early warning signs of children's mental health conditions. There is a need to develop and implement protocols to assist and refer children in crisis.

Primary components of the Children's Mental Health Crisis and Stabilization Plan, for children ages two through seventeen, include: 1) Development of a Mobile Crisis Team for referrals of children and youth using a "no wrong door" approach; 2) Enhancement and expansion of current Francis Lauer/YSS services for youth ages twelve through seventeen; and 3) implementation of services for children ages two through eleven. The program service design was submitted in the Francis Lauer/YSS report submitted in December 2016.



Projected long-term outcomes that may result from the implementation of this plan include:

- Decreased number of children experiencing (re)traumatization
- Decreased number of children involved with the IA Dept. of Human Services and Juvenile Court Services, Second Judicial District
- Reduction in the % of adolescents presenting to Mason City Mercy Medical Center Emergency
   Department with a crisis who are admitted to the psychiatric unit (where beds are available)
- Reduction in the number of children presenting at Mason City Mercy Medical Center
   Emergency Department with a crisis
- Reduction in repeat visits to Mason City Mercy Medical Center Emergency Department related to mental health by individual children
- Increase in the number of mental health services available for children in the seven county
   North Iowa area
- Decreased incidence of future crisis (among those who have received services)
- Increase the number of non-hospital referred youth receiving services within 5 days
- Decreased number of weekly in-home crisis incidents reported by parents participating in stabilization services

Services developed under this Children's Mental Health Crisis and Stabilization plan provide timely access to services via multiple potential community partner referral sources and place less stress on families, while providing both intensive clinical and skill building individually tailored sessions to parents and youth, as compared to PMIC placement. A smaller number bed days (average of fourteen days for adolescents and five days for children/parents) added to outpatient therapy, if needed, and in-home skill building visits also results in less treatment cost as compared to the average PMIC placement for youth (120-150 days).



#### 1.3.1.1.1-GEOGRAPHIC AREA:

The geographically defined area addressed in this report to develop a children's crisis mental health plan continues as the seven contiguous North Central counties of Cerro Gordo, Chickasaw, Floyd, Hancock, Mitchell, Winnebago, and Worth counties.

#### 1.3.1.1.2- PLANNING WORK GROUP AND STAKEHOLDER INPUT IN THE PROCESS:

### **Planning Work Group Partners:**

The original 11 member Planning Work Group continued to meet January through June 2017. The following group membership changes occurred during this time period:

- Mary Schissel retired as Youth Task Force Director in April 2017, but continued to participate in the Planning Work Group as parent/consultant.
- Alice Ciavarelli, new Mason City Youth Task Force Director, joined the group.
- Sarah Knudsen, Regional Administrator, Region 2, Central Rivers AEA and Carol Sensor, Regional Administrator, Region 3, Central Rivers AEA participated in the planning group.
- Stacy Olsen DiStefano, M.C., Vice President of Innovation, Resources for Human Development, Philadelphia PA advised the group.
- Kara Vogelson, Planner, Cerro Gordo County Dept. of Public Health assisted the Data/Metrics/Indicator Subcommittee.

#### **Group Activity**

Eight (8) Planning Work Group meetings were held January-June 2017. Copies of the sign-in sheets are attached to this report (page 104). In addition, Jean McAleer and Brigid Christianson participated in a site visit to Autumn Center at Seasons Behavioral Center in Spencer on March 8th to explore physical design for the children/family shelter and programming for the project.

The group was made aware that County Social Services would not be able to fund startup of this service as planned at their meeting on June 22. This news impacted the timeline of future work. The group had initially projected a service implementation date of October 2017. Another development that will impact mental health service provision for children and adolescents is the merger of WellSource, a primary mental health provider, with Prairie Ridge Integrated Behavioral Health that is currently in process.



At the Planning Work Group meeting, held January 20, 2017, members reviewed the December report submitted to DHS and held a group discussion on whether there truly is a need for this type of crisis and stabilization service for children, based on what we have learned so far. The group confirmed there was a strong need, with members sharing their rational for this confirmation.

At the group meeting, held February 9, 2017, the UNI team updated members on progress of the needs assessment/evaluation. They shared that all in-depth interviews were complete and that the parent questionnaire was ready to launch. Monica Paulsen, County Social Services, updated the group on their Board meeting and the group discussed the contracting process. The UNI team and Mary Schissel facilitated the group in constructing a logic model for the project. The logic model is included in the UNI-CRBR document, "Children's Mental Health Crisis Planning: Final Results from a Needs Assessment of Seven Iowa" attached to this report.

At the Planning Work Group meeting, held on March 2, 2017, the UNI team shared gaps identified from the initial review of the in-depth interviews. The group reached consensus on using the *Ages and Stages* assessment tool for children ages 2-11. A brief review of this tool can be found in the "Brief review of the Ages and Stages Questionnaires, 3rd Edition (ASQ-3) and the Ages and Stages Questionnaires: Social-Emotional, 2nd Edition (ASQ: SE-2)" attached to this report (page 28). Group members shared information on upcoming trainings related to children's mental health services. The group discussed a variety of MOUs that will be needed for this project with other providers and community partners. The meeting resulted in the establishment of seven subcommittees, designed to help complete the implementation planning process: Data/Metrics/Indicators; Screening and Assessment: Staffing and Training; Therapeutic Classroom; Awareness and Marketing; Post-service Protocol; and Infrastructure. Each subcommittee addressed the purpose and objectives identified using the logic model constructed at the February 9<sup>th</sup> Planning Work Group meeting.

Jean McAleer and Brigid Christianson shared impressions gathers from the Autumn Center visits in Spencer at the March 20, 2017 Planning Work Group meeting. The UNI team shared the draft of the report of the results of the in-depth interviews with the group. The draft logic model was shared by UNI and updated by the group.

At the Planning Work Group meeting, held on April 20, 2017, Monica Paulsen, Bob Lincoln, and Jean McAleer reported the positive outcome of the meeting and Jean's presentation to the Lt. Governor and DHS Director with County Social Services. The group discussed next steps in data gathering, certification from Commission on Accreditation of Rehabilitation Facilities (CARF), and subcommittees. They also reviewed the second draft of the Qualitative Needs Assessment shared



by Mary Losch and began the discussion of a kickoff event in August as a partnership between YSS/FLYS, County Social Services, and the Mason City Youth Task Force.

Group members toured the facility planned for use as the children/family shelter at their meeting on May 3, 2017. A list of modifications and enhancements for the building was constructed to make it more child/family friendly. Belinda Meis and Andrea Dickerson, YSS staff in Ames, joined the meeting via conference call and discussed CARF certification, electronic medical records, and indicators with the group. The UNI team shared preliminary results of the stakeholder/professional and parent surveys with the group members. Subcommittee conveners and meeting dates were identified at the meeting.

Group members worked on development of the kickoff event, scheduled for August 10, 2017, at the meeting held June 8. The original plan was for a speaker in the morning and a training session for professionals in the afternoon, but after further discussion, the group decided the best approach was to share what we have learned through the UNI research and other activities with professionals and community partners in the afternoon and with parents in the evening. Jean McAleer updated the group on the Child/Family program building site and Belinda, YSS in Ames, updated the group on CARF certification requirements. The subcommittees updated the large group on their work. Eva, UNI, reported on the highlights from the Executive Summary from the draft report of the Parent Survey & Focus Group Findings.

At the Planning Work Group Meeting on June 22, 2017, the group discussed the awareness event planned for August 10, 2017. Subcommittees updated the group on the activities assigned to them and the UNI team informed the group that the final needs assessment report is finished and will be forwarded to the group next week. Bob Lincoln shared information about the re-alignment of County Social Services staffing and how their current budget will not be able to fund the implementation of the services for this project as originally planned. The group discussed potential funding sources for the Children's Mental Health Crisis and Stabilization efforts. The group agreed to meet in July and August to continue working to identify implementation needs and potential funding sources.



### Subcommittee Activity

#### 1. Data/Metrics/Indicators: Leader-Mary Losch / Seven members

PURPOSE: To establish a process that will enable individual and community change, resulting from the Children's Mental Health Crisis and Stabilization project work, to be measured.

OBJECTIVE I: Identify existing and potential new appropriate archival data that will enable measurement of change at the community level.

OBJECTIVE II: Identify existing and potential new appropriate individual metrics that will enable measurement of change at the individual and client group level.

OBJECTIVE III: Construct a data collection plan that will ensure regular and timely collection and sharing of archival and individual data to measure change.

Logic Model Activities	Subcommittee Activity as of 6/30/17
	A listing of potential internal (YSS client data) and external (community population level data) variables were developed by the
Review and select	group. The group researched the GPRA measures and NOMS used
existing sources of data	by SAMHSA to compare to the listings of data. They also identified
for monitoring	the need to research Iowa DHS and IDPH outcome data measures.
	A listing of these measures is included in section 1.3.1.1.4-DATA
	COLLECTION of this report.
Review and add key	YSS is in the process of setting up their new electronic records
variables for intake and	system and will not be able to provide a full list of variables they
exit process	are collecting for the group to review until this activity is complete.
Collect and disseminate	The development of items for this evaluation was put on hold due
ongoing evaluation	to the fact that funding is no longer available for implementation at
feedback from users and	this time.
community partners	
	This measurement tool will be developed and integrated into
Administer youth and	services for youth, ages 12-17, currently being served by FLYS/YSS
parent perceived self-	in relation to the assessment tool used for this age group. The data
efficacy measures for	subcommittee will advise on tying this tool back to the outcome
managing children's MH	variables. Adult and youth post-discharge follow up assessments
issues	will also contain questions related to these measures. Sample draft
	assessments can be found on pages 100-103 of this report.



#### 2. Screening and Assessment: Leader-Brigid Christianson / three members

PURPOSE: To develop a screening and assessment process for FLYS Children's Mental Health Crisis and Stabilization work.

OBJECTIVE I: To develop an implementation plan for a common children's mental health screening tool and process, that is easily used by trained crisis team members, across the North Iowa area.

OBJECTIVE II: To develop an implementation plan for a children's mental health assessment tool and process used by FLYS Children's Mental Health Crisis and Stabilization project staff that is compatible with tools and processes used by other North Iowa youth and children's mental health providers.

Logic Model Activities	Subcommittee Activity as of 6/30/17
Review, select, train, and implement a common screening tool for use by FLYS crisis team members	The UNI team prepared a report: "Trauma screening instruments for children: A brief review" and submitted it to the large group for review in June 2017. The document is included as an attachment to this report (page 22).
Review, select, train, and implement a common assessment tool for use by FLYS mental health providers	Identified training includes instruction on using <i>Ages</i> and <i>Stages</i> ( ASQ-3)for children ages one to three and Connors 3 Inventory for youth ages twelve to seventeen.

#### 3. Staffing and Training: Leader-Jean McAleer / four members

PURPOSE: To develop a staffing plan for implementation of all components of the Children's Mental Health Crisis and Stabilization work.

OBJECTIVE I: To develop a clinical staffing plan for Children's Mental Health Crisis and Stabilization work.

OBJECTIVE II: To develop a staffing plan for the Children's Mobile Crisis Team.

OBJECTIVE III: To develop a staffing plan for the children's/family shelter.

OBJECTIVE IV: To develop a staffing plan for Children's Mental Health and Crisis Stabilization outreach/skill building.

Logic Model Activities	Subcommittee Activity as of 6/30/17
Recruit, hire, and train shelter staff	Staffing for services to children, ages 2-11, has been put on hold due to lack of funding Additional training for staff serving youth, ages 12-17, will be identified once the impact of closure of WellSource, a primary mental health provider for our area, is known. Currently identified additional training consists of Youth Mental Health First Aid training and trauma informed approaches.
Recruit, hire and train staff	The Mobile Crisis Team component has been put on hold due
for the Mobile Crisis Team	to lack of funding.



#### 4. Therapeutic Classroom: Leader-Jadie Meyer / four members

PURPOSE: To develop a summary of therapeutic classroom research and recommendations for the FLYS shelter classrooms as part of the Children's Mental Health Crisis and Stabilization project.

OBJECTIVE I: To develop a research summary of therapeutic classrooms to be used as a rationale for inclusion of therapeutic classrooms at FLYS.

OBJECTIVE II: To develop recommendations, including best practices, for implementation of therapeutic classrooms at FLYS.

Logic Model Activities	Subcommittee Activity as of 6/30/17
Gather information and provide a summary of therapeutic classrooms	The Therapeutic Classroom subcommittee has begun collaboration with Karen Aldrich, Regional Administrator with Central Rivers Area Education Agency, to discuss recommendations and best practices for implementation of therapeutic classrooms. The importance of recognizing both internalizing and externalizing factors and signs has been highlighted as an area of critical importance. Central Rivers AEA has developed a course: "Mental Health-An Overview of Educators". Eight of the sixteen school districts in the seven county area have had at least one staff complete the course. The AEA will be scheduling this course again in the upcoming months. The subcommittee continues to attempt to network with model therapeutic programs throughout the state.

#### 5. Awareness and Marketing: Leaders-Bob Lincoln and Jean McAleer / 4 members

PURPOSE: To develop a plan to make various community sectors aware of Children's Mental Health Crisis and Stabilization Services and how to access services.

OBJECTIVE I: To develop a broad-based, comprehensive marketing plan for Children's Mental Health Crisis and Stabilization Services.

OBJECTIVE II: To identify resources able to assist with implementation of a marketing plan for Children's Mental Health Crisis and Stabilization Services.

Logic Model Activities	Subcommittee Activity as of 6/30/17
Develop a formal marketing plan	Originally, a plan was discussed to make all referral partners, providers, parents and others aware of Children's Mental Health Crisis and Stabilization Services. When notified that funding for implementation was no longer available, the marketing awareness efforts shifted to sharing the research conducted by the UNI team and information about existing resources at a summit scheduled for August 10, 2017. The Mason City Youth Task Force is working on production of "Save the Date" and invitation materials. YSS/FLYS, the Mason City Youth Task Force, County Social Services, and other Planning Group members will assist with distribution of information about the event.



#### 6. Post-Service Protocol: Leader-Jean McAleer / 5 members

PURPOSE: To develop a plan and procedures for post-crisis and stabilization services that will help ensure continued services are easily accessed by families and children if needed and that will inform evaluation of the program.

OBJECTIVE I: To develop a contact plan that includes timelines, procedures, and content for post-crisis and stabilization follow-up for families and children.

OBJECTIVE II: To incorporate collection of evaluation measures, as recommended by the Data Subcommittee, into the post-service plan.

Logic Model Activities	Subcommittee Activity as of 6/30/17
Develon nost-service protocol	30 and 60 day post-discharge follow up client surveys for
	both adults and youth have been developed and are included
	as attachments to this report. YSS internal and archival
	external outcome measures are contained in the surveys.

#### 7. Infrastructure: Leader-Jean McAleer/ All members

PURPOSE: To develop a funding plan and implementation plan that addresses all necessary licensure and requirements.

OBJECTIVE I: To identify activities needed to obtain CARF certification for all services and licensure for the shelters.

OBJECTIVE II: To identify potential funding sources for implementation of the Children's Crisis and Stabilization services.

OBJECTIVE III: To develop a plan to modify the proposed children and family shelter building as appropriate for young children and to meet certification and licensure requirements.

Logic Model Activities	Subcommittee Activity as of 6/30/17
Coordinate with YSS to identify CARF requirements and develop plan for implementation	FLYS/YSS will move forward with CARF certification for the Mason City location based on a timeline with other YSS certifications. FLYS staff is working with Ames staff to provide all information needed.
Design and name family shelter	Postponed due to lack of funding.
Complete any necessary remodeling and landscaping	Postponed due to lack of funding.
Determine and obtain appropriate licensure	Postponed due to lack of funding.



# Input and direct involvement of families of children with a mental health diagnosis and children/youth with a mental health diagnosis:

Twenty-two community partner interviews were conducted during phase one of the study. Parents were engaged by the UNI team in identification of needs and issues through focus group discussions and telephone surveys January-April 2017. A total of 270 parents provided input to the process. Twelve of these parents participated in focus groups and 258 participated in the telephone surveys.

Youth were engaged by the UNI team in identification of needs and issues through focus group discussions, January-April 2017. A total of fifteen youth at the Mason City Alternative High School and Francis Lauer Youth Services participated in focus groups.

Process information and results of parent and youth engagement are included in the UNI report, "Children's Mental Health Crisis Planning: Final Results from a Needs Assessment of Seven Iowa Counties", included as an attachment to this final report. Main themes from the community partner interviews, focus groups, and telephone survey are contained in the Executive Summary of the UNI report.

# Use of a collaborative process identified in the Children's Mental Health and Well-Being Planning Work Group Final Report:

The FLYS/YSS Planning Workgroup followed the collaborative process described on page three of <a href="https://example.com/html/>
The Iowa Department of Human Services The Children's Mental Health Study Report December 15, 2016">2016</a>:

"The Workgroup agreed there are a number of community entities, including mental health providers, which contribute to the enhanced wellbeing of children and families. While each of these entities can and do contribute to child and family wellbeing, none of them has the authority or the financial responsibility to ensure children and families receive prevention and early intervention services. The Workgroup believes that if these community entities worked together in a constructive and collaborative fashion while at the same time maintain integrity of each of their roles:

- Children and families will experience improved wellbeing;
- Prevention will be more effective for children, families and the community at large; and
- Existing available resources will be used much more efficiently."



The Planning Group structure and process, described in the December 2016 report, ensured ongoing engagement and communication among key organizations involved with children/youth mental health in the geographic area. Organizational representatives held a total of twelve large group meetings from October 2016 through June 2017. Meeting minutes were shared via email after each meeting to allow those not able to attend the meeting to ask questions and provide input on the meeting content and outcomes. In addition, group members made contact with others in their community sector outside of meetings to discuss the project and shared input from others at the meetings.

The afternoon of the public event, scheduled for August 10, 2017, will serve as the vehicle to engage other community partners, who have not been directly engaged in the Planning Group, by sharing outcomes of the research conducted by UNI and the proposed plan outline developed by group members. This format will also provide a venue for a wide variety of organizations to share information on their needs, current services, and future plans related to children's mental health. Advisory organizations listed in the December 2016 report, as well as educators and administrators from across the AEA area; local, state, and elected officials; state department representatives; the faith community; county public health department representatives; law enforcement; and other community sector representatives will be invited to the afternoon session.

The evening session of the August 10<sup>th</sup> event will focus on parents and family members as well as the general public to share the research and the plan. This will provide a venue for expanded input for future implementation plans.



# LEARNINGS TO DATE FROM THE PLANNING WORK GROUP AND STAKEHOLDER INPUT PROCESS:

The approach, structure, and process proposed in the FLYS/YSS Children's Mental Health Crisis and Stabilization plan has been validated as having a strong potential to impact children and family mental health and well-being through the research conducted by the Center for Social and Behavioral Research at the University of Northern Iowa. Youth, parent, and community partner input has re-enforced the emerging themes identified by this research. AEA representatives shared the information on a mental health survey they conducted with administrators and counselors at all 52 school district in their area during the 2016-2017 school year. A verbal report from AEA staff to the Data/Metrics/Indicators Subcommittee indicated results of this survey mirrored the information obtained by the UNI team from community partners, parents, and youth.

There is minimal best practice research currently available for the needs and issues of young children, ages 2-11, to be addressed by this project. This was noted in the UNI-CBR report, "School-based interventions in child health: A summary of recent findings" submitted as an attachment to the FLYS/YSS report to the Iowa Department of Human Services. No additional significant best practice research has been identified since the submission of this report. The development and implementation of prevention, intervention, and treatment for young children will need to draw upon research conducted for older youth and combine it with the limited research available for the younger age group.

If crisis and stabilization service implementation is to be effective, it will require raising awareness and engagement of a wide variety of community sectors in order to implement a comprehensive "no wrong door" approach that will help ensure early identification and intervention. Time and financial support for development and implementation of this engagement needs to be a part of the overall initiative in addition to actual services for children, youth, and their families.

It is the consensus of the FLYS/YSS Planning Work Group that implementation of the Children's Mental Health Crisis and Stabilization Services could have a broad impact on the lives of children and their families beyond the immediate mental health crisis. The group would like to see a long-term evaluation developed in tandem with implementation of these services in order to measure the true impact of efforts and add to the body of research available on this subject.



# 1.3.1.1.3-PROPOSED CHILDREN'S CRISIS MENTAL HEALTH CRISIS RESPONSE SYSTEM

The proposed structure and operation of the Children's Crisis and Stabilization Services submitted in the December 2016 report to the Iowa Department of Human Services remains the recommended system of the FLYS/YSS Planning Work Group for our North Central Iowa area. As described in the earlier report, this system contains the following components:

- 1. Broad community-based identification, screening and referral to initial services for young people ages two (2) to seventeen (17), including availability of a Kids' Mobile Crisis Team.
- 2. Determination of the need for hospitalization or community-based/intensive services.
- 3. Provision of flexible crisis and stabilization clinical and skills development services, including a short-term family shelter for children ages 2-11 and an adolescent shelter for youth ages 12-17.
- 4. Engagement of other pre-existing clinical providers, schools and family support team resources.
- 5. Post-service support for the child/adolescent and their family.



# LEARNINGS TO DATE FROM THE DEVELOPMENT OF A CHILDREN'S MENTAL HEALTH SERVICES SYSTEM:

One measure of mental health crisis taken into account when developing the plan for this report was the number of young children seen by the local hospital emergency department who were discharged from emergency services to their home. According to Rose Brantner, Director of Mercy Behavioral Health in Mason City, 79 children, age twelve and under, were seen with mental health issues by their hospital's Emergency Department in 2016. 75% of these children (59) were discharged home from the Emergency Department and 22% (17 children) were transferred to another hospital or facility. These numbers illustrate a clear need for a better system to serve these young people and their families. It is also clear that there is not currently funding or capacity to provide the needed services.

State, regional, and local budgets and resources have become fast-shifting sands over the past six months that have impacted the development of this plan for our area. Initial assumptions regarding the funding of the start-up of these services for our area are no longer true due to changes in the County Social Services budget.

Available local resources are in the process of being impacted by the merger in progress between WellSource, a primary mental health provider, with Prairie Ridge Integrated Behavioral Health, another local resource. While this merger will not be final until August 2017, initial plans are for Prairie Ridge to work primarily with adults, and to refer youth to Francis Lauer Youth Services. This will present a capacity challenge to Francis Lauer/YSS that must be managed within the next twelve months. Youth and Shelter Services is working diligently to shore up staffing needed to serve additional youth, ages twelve to seventeen, anticipated to be referred. There are inadequate resources to incorporate service to children, ages two to eleven, related to this plan.

School district budget have been severely impacted by the state budget. The staffing outcomes of this impact remain to be seen. Both service provider and education staffing changes may increase the staff needed for implementation of Children's Mental Health Crisis and Stabilization Services across many sectors for our area.



#### 1.3.1.1.4-DATA COLLECTION

#### **Needs Assessment:**

The Center for Social and Behavioral Research at the University of Northern Iowa submitted the final needs assessment, "Children's Mental Health Crisis Planning: Final Results from a Needs Assessment of Seven Iowa Counties", to the Planning Work Group in June 2017. This report is included as an attachment to this final report (under Attachments, page 38 of 165). All components of this report were shared with the Planning Work Group as they were developed. The group provided input on the report and suggested additional research or information to be gathered.

#### **Outcome Measures**

Proposed outcomes were identified by the Planning Work Group, based on the logic model developed by the group. The Data/Metrics/Indicator Subcommittee, facilitated by Mary Losch, CSBR-UNI, drilled deeper into the outcomes to identify proposed measures and conduct research on the availability of data. Outcome measure data projected to be available internally from YSS is listed below:

Outcome	Proposed measure(s)
Decrease the interval between discharge and first follow-up	- Date of discharge
service	- Follow-up date
Increase the % of parents (participating in services) who perceive	- Ability to cope item administered
they are better able to help their child	pre/post
Increase the % of youth who perceive they are able to manage	- Ability to cope item administered
their mental health issues most of the time	pre/post
Decrease number of children experiencing (re)traumatization	- Trauma measures
	- Number of children receiving services
Increase the number of kids who receive services for mental	from YSS
health screening and treatment	- Demographics of clients/families
	(annual basis)
Decrease the incidence of future crisis (among those who have received services)	- Crisis service dates over time
Increase the number of non-hospital referred youth receiving	- Referral date
services within 5 days	- Referral source
Decrease the number of weekly in-home crisis incidents reported	- Number of crisis incidents reported by
by parents participating in stabilization services	parents



External outcome measure data to be gathered from sources, other than YSS, is listed in the following table:

Outcome	Proposed measure(s)			
Increase in the number of instructional minutes for both children and adolescents	- Number of instructional minutes			
	- Waiting list for PMIC			
Decrease the number of children needing DMIC care	- PMIC admissions			
Decrease the number of children needing PMIC care	<ul> <li># of children engaged in alternative treatment</li> </ul>			
Decree the content of diller in the design of the DUC and DCC	- # of children involved with DHS			
Decrease the number of children involved with DHS and JCO	- # of children involved with JCO			
Reduction in the number of children presenting at the ED with a	- # of children presented at the ED with			
crisis	a crisis			
Reduction in repeat visits to the ED related to mental health by	- # of children presented at the ED with			
individual children	mental health issues			
Decrease the incidence of future crisis (among those who have	Cuicido votos			
received services)	- Suicide rates			

Contact organizations and individuals to provide external data have been identified and contacted by subcommittee members to ascertain if this information is available in the format needed. To date, the vast majority of those contacted have responded in the affirmative regarding data availability and willingness to provide data.



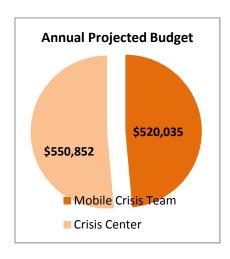
**Process Measures:** Client and service process measures will be part of the electronic medical records system of YSS.

#### **LEARNINGS TO DATE FROM DATA COLLECTION EFFORTS:**

The Planning Group recognizes that data collection for these efforts needs to be structured in a manner that common indicators will link with projects and funding sources across sectors in order for the information to be useful. NOMS and GPRA measures from SAMHSA are being compared by the Data/Matrix/Indicator Subcommittee to the outcomes listed in the tables above. The group also plans to gather DHS and IDPH information on data collected by these departments and compare project indicators to the proposed outcome measures.

#### 1.3.1.1.5-FUNDING PROCESS AND PROPOSED BUDGET

The following budget is a nine month revenue/ developed expense budget prior announcement from County Social Services that they will not be able to fund this project. The budget is also revised from the December 2016 submitted report. Projected total annual expense to serve 139 children and youth under the project would be \$1,070,887. The Mobile Crisis Team represents 48.6% of total cost and the Crisis Center represents 51.4% of total cost. The mobile crisis team is the lease restrictive and thus most cost effective and the intensive services providing the most intensive intervention, is most costly. It is estimated that these services reduce the number of children who are removed from their homes and placed in PMIC's.





			Patients	Total Billings Per Pt		Total Revenue			obile risis		Cris	
		-	, defents		-0	Total Nevenue		3rd Party	11313	CSS	3rd Party	CSS
SD SIGN Development Services			40					50%		50%	50%	50%
CB Skill Development Services	Initial	Fval	40	213	75%	\$ 6,390	\$		\$	6,390		
	Assess			350	75%	10,500	,		Ş	10,500		
	BHIS			2,743		82,291		41,146		41,146		
	Thera	ру		-	75%	,		-		-		
		ervice Check-i	n	50	75%	1,500				1,500		
			0.000				1					
CB Skill Development & Clinical S		e	40				1					
	Initial Assess			213	75%	6,390				6,390		
	BHIS	iment		350	75% 75%	10,500 69,433		34,717		10,500		
	Thera	nv		2,314 3,073	75%	92,182		46,091		34,717 46,091		
		ervice Check-ii	n	50	75%	1,500		40,031		1,500		
				-		-,	1			-,		
Child / Family Intensive Services			24									
	Initial			213	75%	3,834						3,83
	Bed Fe			2,625	75%	47,250						47,25
	Assess	sment		350	75%	6,300						6,30
	BHIS			2,314	75%	41,660					20,830	20,83
	Therap			3,073	75%	55,309	1				27,654	27,65
	POST S	ervice Check-ii		50	75%	900	1					90
Adolescent / Family Intensive Ser	vices		35									
	Initial	Eval	pa 20	213	75%	5,591.25	1					5,59
	Bed Fe	ees		3,500	75%	91,875						91,8
	Assess	ment		350	75%	9,187.50						9,18
	BHIS			2,486	75%	65,254.35	İ				32,627	32,62
	Therap	No.		3,512	75%	92,181.60	1				46,091	46,09
	Post S	ervice Check-ir	1	50	75%	1,312.50						1,31
Annual Crisis Line Management				10,000	75%	7,500				7,500		
Program Oversight (CSS Reimbur: Program Director	sement)			7,975	75%	5,981				5,981		
Program Director	Tota	l Revenue	139	72,000	75%	\$ 768,822	\$	121,953	c	27,000 199,214	\$ 127,202	27,00 \$ 320,45
							1			/	,	7 320,10
Expenses												
Childrens Mental Health Team:				*	75%							
Program Manager	\$	38,000	1	38,000	75%	28,500		7,125		7,125	7,125	7,12
Program Director	\$	72,000	1	72,000	75%	54,000		-		27,000		27,00
Clinical Director	\$	70,000	1	70,000	75%	52,500		13,125		13,125	13,125	13,12
Gatekeeper	\$	37,440	0.25	9,360	75%	7,020		1,755		1,755	-	3,51
Intensive Therapist	\$	60,000	2	120,000	75%	90,000		22,500		22,500	21,086	23,91
Mobile Crisis Phone	\$	10,000	1	10,000	75%	7,500				7,500		
Mobile Crisis Team/ In-Home	\$	42,280	4	169,120	75%	126,840		17,280		109,560		
2-11 Crisis center Staff	\$	37,440	4	149,760	75%	112,320						112,32
Shelter Staff 12-17	\$	37,440 101,150	1	37,440	75%	28,080		15 445		47.444	40.004	28,08
Fringe Benefits & PR Tax	Þ	101,150	25%	101,150	15%	126,690		15,446		47,141	10,334	53,76
Total Payroll						633,450		77,231		235,706	51,670	268,84
6-12 Child Family Intesive In-Pat	ont Ow	arboad Costs										
0-12 Clina ranniy intesive in-rat	ent Ove	erneau costs	Est. Miles	Rate								
Mileage		_	4000	180	75%	1,110				1,110		
Psych Consult. Encounters		-		\$ 175	75%	74				-		
Vehicles				17. 22.0	75%							
Technology				6,143	75%	4,607				2,304		2,30
Phones	Dollar		15	6,300	75%	4,725				2,363		2,36
Depreciation Depreciation	Buildin	-		15,000	75%	11,250				5,625		5,62
Depreciation Depreciation	Equipn Vehicle			13,000 10,000	75% 75%	9,750 7,500				4,875 3,750		4,87
Telephone	Verneit			2,500	75%	1,875				1,875		3,75
Office Supplies				4,500	75%	3,375				1,688		1,68
Maintenance				4,000	75%	3,000				1,500		1,50
Utilities				7,000	75%	5,250				2,625		2,62
Vehicle Expense				2,000	75%	1,500				750		75
Rent					75%	-						-
Food Expense				-	75%					-		-
Total Overhead Costs						53,942				28,464	-	25,47
Administrative Cost						115,323		18,293		29,882	19,080	48,06
Total Program Costs				5,774.93	-	802,716		95,524		294,052	70,750	342,38
Total Trogram Cools											_	
Net Margin					-	\$ (33,893)	c	26,429	ć	(94,838)	\$ 56,452	(21,93

MCO	\$ 249,155	
CSS	\$ 553,560	(Injudes Revenue coverage for non-covered clients, plus allocated expenses)



## 1.3.1.2.3-441 IOWA ADMINISTRATIVE CODE, CH.24, DIV. II

Upon review of the Administrative Code, CH. 24, the Pediatric CH 24 will be applied for. YSS has Chapter 24 status and will add the necessary information and data to become Pediatric CH 24 eligible. The Planning Group has agreed to search for alternative funding sources that will allow the Children's Mental Health Crisis and Stabilization plan to move forward. This may require breaking up components of the plan to fit funding criteria as the group feels it doubtful that a single funding source can be found to cover total cost of the plan.



# **ATTACHMENTS**



# Trauma screening instruments for children: A brief review

### **Prepared by**

Eva Aizpurua, PhD Mary E. Losch, PhD Center for Social and Behavioral Research University of Northern Iowa

#### **Prepared for**

Youth & Shelter Services

June 2017





# Trauma screening instruments for children: A brief review

#### Introduction

According to the most recent data (Sacks, Murphy & Moore, 2014) 46% of children in the United States have been exposed to at least one adverse childhood experience, such as economic hardship or living with a parent who has an alcohol- or drug-use problem. In lowa, the most common adversities experienced by children are divorce or separation of a parent (22%), economic hardship (22%), living with someone who has an alcohol or drug problem (13%), and living with someone with a mental illness (13%). Although lowa is in the lowest quartile for three potentially traumatic experiences (economic hardship, violence in the neighborhood, and death of a parent), it is also among the states with the highest prevalence of children living with someone with mental illness.

A recent systematic review of longitudinal studies suggested that in the aftermath of traumatic events, approximately 20% of children experience posttraumatic stress disorder (Hiller et al., 2016). Additionally, childhood exposure to trauma has been found to predict negative physical and mental health (Flaherty et al., 2006: Flaherty et al., 2013: Finkelhor, Shattuck, Turner & Hamby, 2015), premature death, behavior problems (Steinberg et al., 2013), and risky behaviors (Layne et al., 2014). The associations between trauma exposure and poor mental and physical health outcomes appear to begin as early as 6 years of age (Flaherty et al., 2013). These findings underscore the value of developing a trauma-informed approach to child services. Despite the growing evidence base, relatively few instruments have been validated as trauma screening tools for children.

#### Objective

This document briefly reviews the literature concerning the properties of widely used, existing assessment instruments, including the Child Trauma Screen (CTS, Lang & Connel, 2017), the UCLA Child/Adolescent PTSD Reaction Index, the Adverse Childhood Experiences Inventory (ACEs), and the Child and Adolescent Trauma Screen (CATS).

### The Child Trauma Screen (CTS)

The CTS is a brief screening tool for four potentially traumatic events and six trauma symptoms. This instrument is designed to be administered by trained clinical and non-clinical staff (e.g., child welfare workers, juvenile probation officers, school personnel).

#### **Administration**

There are two versions of this tool (see appendix A):

- 1. The child report (intended for children 7 and older), and
- 2. The caregiver report (targeting caregivers).

Both versions can be administered as self-reports or as interviews. It is advisable to administer both versions, as parent-child reports of trauma exposure and reactions are only moderately correlated. The instrument is also available in Spanish.

#### Scoring

The first four items (yes/no questions) are summed to indicate the number of potentially traumatic events experienced by the child (0 to 4). The following six items (measured on a 4-point scale) are summed to provide a reaction score that ranges from 0 to 18. The optimal cut scores for this reaction score are 6 or greater on the child report, and 8 or greater on the caregiver report (Lang & Connel, 2017).



#### Validation

The CTS shows good internal consistency ( $\alpha$ =.79 for children and  $\alpha$ =.82 for parents), strong convergent and divergent validity, and strong predictive accuracy. For the caregiver report, a cut-off of 8 or greater correctly classified 92.5% of the children (sensitivity: 1.00, specificity: 0.90). For the child report, a cut-point of 6 correctly classified 87.5% of the children (sensitivity: 0.88, specificity: 0.88).

#### Limitations

The instrument needs further validation. The sample size of the validation study was relatively small (n=74 children aged 6-17).

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Measure	The Child Trauma Screen (CTS)
Audience	Clinical and non-clinical staff
Target age group	6-17
Corresponded to DSM criteria	Yes
# items	10 (4 traumatic events, 6 trauma symptoms)
Traumatic events	Witnessing violence, victim of violence, sexual abuse

Table 1. Main characteristics of the Child Trauma Screen (CTS)

#### The UCLA Child/Adolescent PTSD Reaction Index (UCLA-RI)

The UCLA PTDS-RI is a screen tool for trauma and symptoms using DSM-V criteria among children ages 6 to 17. This instrument is intended for use by qualified mental health providers and researchers (a licensing agreement is required for the use of the Index).

#### Administration

There are three versions of this tool:

- 1. The child report,
- 2. The adolescent report, and
- 3. The caregiver report (targeting caregivers).

Translations of the instrument exist in Spanish and German. The three versions can be administered verbally or completed by the individuals themselves.

#### Validation

The PTSD-RI versions have displayed good to excellent internal consistency ( $\alpha$ =.89-.91) and strong convergent validity in large samples of children (Elhai et al., 2013: Steinberg et al., 2013). Despite their satisfactory metric properties, the scale has not showed evidence of adequate discriminant validity (Steinberg et al., 2013).

#### Limitations

- Cut-off scores based on sensitivity and specificity of the instrument are not determined.
- The instrument did not provide evidence of discriminant validity.

Table 2. Main characteristics of the UCLA PTSD Reaction Index

Measure	The UCLA PTDS Reaction Index
Audience	Qualified mental health professionals and researchers



Target age group	6-17
Corresponded to DSM criteria	Yes
# items	37 (20 traumatic events, 17 trauma symptoms)
Traumatic events	Sexual abuse, physical abuse, emotional abuse, neglect, domestic violence, war/terrorism/political violence, illness/medical trauma, injury/accident, natural disaster, kidnapping, traumatic loss, forced displacement, impaired caregiver, extreme personal/interpersonal violence, community violence, school violence, and other trauma

#### The Adverse Childhood Experiences Inventory (ACE)

The Adverse Childhood Experiences Inventory is a 10-item measure<sup>1</sup> that assesses potential traumatic events related to emotional/physical abuse, sexual abuse, and household dysfunction. Items are rated on a yes/no scale (see Appendix B).

#### Scoring

The 10 items are summed to provide an overall adversity index with scores ranging from 0 (adversities absent) to 10 (all adversities present).

#### **Limitations**

- Although the ACE inventory is widely used, most of the literature is based on adult retrospective measures of childhood experiences and the ACE has not been validated in samples of children. There is little information about its factor structure and metric properties and the available information is based on adult samples (e.g., Ford et al., 2014).
- The studies in which the ACE inventory was applied to children suggest that some of its items (parent's divorce/separation and incarceration of a household member) do not predict physical or mental health outcomes as expected, thus, reducing the predictive validity of the inventory (Finkelhor, Shattuck, Turner & Hamby, 2013; Finkelhor et al., 2015). Furthermore, these recent studies have proposed additional items such as peer victimization, peer isolation, and exposure to community violence for inclusion, as they increase the ability of the inventory to predict health outcomes.
- Additionally, recent studies (e.g. Cronholm et al., 2015) have found that traditional ACEs questions which were originally developed for primarily white, educated respondents- induce artificially lowered rates of adversities among diverse social and racial groups. For this reason, inclusion of community-level indicators (such as experiencing racism, living in an unsafe neighborhood, witnessing community violence, experiencing bullying, and having a history with foster care), have been suggested to improve the predictive validity of the measures.

<sup>1</sup> There is an International version (ACE-IQ, World Health Organization) designed for administration to adults, made up of 43 items.



Table 3. Main characteristics of The Adverse Childhood Experiences (ACE) Inventory

Measure	The Adverse Childhood Experiences Inventory
Audience	Not specified
Target age group	Not specified
Corresponded to DSM criteria	No
# items	10 traumatic events
Traumatic events	Emotional abuse, physical abuse, sexual assault, emotional neglect, physical neglect, mother treated violently, household substance abuse, household mental illness, parental separation/divorce, and incarcerated household members

#### The Child and Adolescent Trauma Screen (CATS)

The CATS is a freely accessible screening tool for traumatic events and trauma symptoms based on DSM-5 criteria. If at least one of the 15 potentially traumatic events is selected, trauma symptoms and psychosocial functioning are measured (CATS Reports can be found in Appendices 3 A to C).

#### Administration

There are three versions of this tool (see appendices C1, C2, and C3):

- 1. The child and adolescent self-report (intended for children 7 and older), and
- 2. The caregiver report for 3- to 6-year-old children, and
- 3. The caregiver report for 7- to 17-year-old children and adolescents.

As children's and parents' reports are only moderately correlated, the authors suggest using both versions whenever possible (Sachser et al., 2017). The instrument is currently available in English, German, Norwegian, and Spanish.

#### Scoring

The first 15 items (yes/no questions) are summed to indicate the number of potentially traumatic events experienced by the child (0 to 15). The next set of items (measured on a 4-point scale) are summed to provide a symptom score that ranges from 0 to 66 for children 7 and older, and from 0 to 48 for children under 7. The optimal cut scores for this symptom score are 12 or greater for preschool children and 15 or greater for children 7 and older (Sachser et al., 2017). Finally, the functioning items assess whether the previously rated symptoms interfere with essential functioning areas using yes/no questions.

#### Validation

The CATS questionnaire proves good to excellent internal consistency in clinical samples of youth ages 3 to 17 ( $\alpha$ =.90-.93 for the self-report version, and  $\alpha$ =.88-.94 for the caregiver versions). It also shows good convergent and discriminant validity with other measures of mental health and posttraumatic stress symptoms (Sachser et al., 2017).

#### Limitations

- Cut-points based on sensitivity and specificity of the instrument are not determined.



Table 4. Main characteristics of the The Child and Adolescent Trauma Screen (CATS)

Measure	The Child and Adolescent Trauma Screen (CATS)
Audience	Not specified
Target age group	3-17
Corresponded to DSM criteria	Yes
# items	15 traumatic events
Traumatic events	Natural disasters, accidents, illness/medical trauma, experiencing or seeing violence at home, experiencing or seeing violence in the community, sexual abuse, traumatic loss, medical procedures, war, and other trauma



Brief review of the Ages and Stages Questionnaires, 3rd Edition (ASQ-3) and the Ages and Stages Questionnaires: Social-Emotional, 2<sup>nd</sup> Edition (ASQ: SE-2)

#### Prepared by

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#### **Prepared for**

Youth & Shelter Services

June 2017





# Brief review of the Ages and Stages Questionnaires, 3<sup>rd</sup> Edition (ASQ-3)

#### Introduction

Developmental delays are frequent in early childhood, affecting 10-15% of children in the United States (Rosenberg, Zhang, & Robinson, 2008). Despite the benefits of early intervention, a large percentage of children with developmental delays are not detected until starting school. The first step to facilitate early intervention is to identify those children who are (or might be) at risk of developmental delays. For this purpose, the American Academy of Pediatrics (AAP) recommends using validated screening tools during visits at 9, 18, and 30 months. In spite of this recommendation, studies conducted in the United States have found that only a minority of children in that age group are formally screened (Radecki, Sand-Loud, O'Connor, Sharp, & Olson, 2011; Rice et al., 2014). Although clinician's use of standardized screening tools have increased in recent years, data from 2009 indicates that half of the pediatricians did not routinely use screening tools with patients under three years at that time (Radecki et al., 2011).

#### Objective

This document provides a brief review of the literature concerning the properties of the Ages and Stages Questionnaires, 3<sup>rd</sup> edition (ASQ-3), in pediatric populations. This tool was chosen considering its popularity (King-Dowling, Rodriguez, Missiuna, & Cairney, 2015; Radecki et al., 2011) and its potential use by Youth and Shelter Services in the future.

In the second part of this document, we provide information about the psychometric properties of the the second edition of the Social-Emotional version of the ASQ (ASQ: SE-2). This measure helps identify young children at risk of socio-emotional problems, that can be used alone or in conjunction with the ASQ.

### Background

The Ages and Stages Questionnaires (ASQ) were developed by Jane Squires and Diane Bricker in the 1980s. The revisions of the questionnaires started in 1991 and the third edition (ASQ-3) was published in 2009 (Squires, Twombly, Bricker, & Potter, 2009). Revisions for ASQ-3 were based on 18,572 questionnaires completed by parents of children under 5.5 years.

#### Purpose of the questionnaires

The Ages and Stages Questionnaires are parent-completed screening tools for determining the need for further evaluation of developmental delay. These tools facilitate early detection of children with developmental problems from birth to 5.5 years.



Table 1. Main characteristics of the Ages and Stages Questionnaires, 3<sup>rd</sup> Edition

Measure name and acronym	The Ages and Stages Questionnaire, 3 <sup>rd</sup> Edition (ASQ-3)
Audience	Parents/ caregivers and providers
Target age group	1 to 66 months
Number of questionnaires	21 (age intervals include 2, 4, 6, 8, 9, 10, 12, 14, 16, 18, 20, 22, 24, 27, 30, 33, 36, 42, 48, 54, and 60 months)
# of items	30 per questionnaire
<b>Developmental domains</b>	Gross motor, fine motor, communication, problem-solving, and
assessed	personal-social
Administration time	10-15 minutes
	Questionnaires and key forms. In addition, a starter kit could be
Equipment needed	purchased to engage children during the administration of the questionnaire.

#### Administration

Parents or practitioners who know the child well answer the questionnaire at one of the 21 age intervals (2, 4, 6, 8, 9, 10, 12, 14, 16, 18, 20, 22, 24, 27, 30, 33, 36, 42, 48, 54, or 60 months). Each questionnaire is made up of 30 items assessing five developmental domains: (1) gross motor, (2) fine motor, (3) communication, (4) problem solving, and (5) personal-social. Additionally, there is an overall section that addresses general concerns that parents might have.

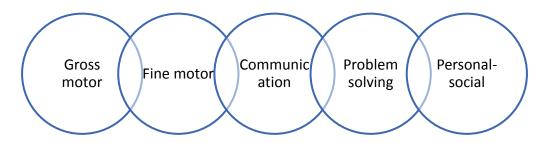


Figure 1. Developmental domains assessed

#### Scoring

Each question has three response options that indicate whether the ability has been developed (yes), is emerging or inconsistent (sometimes), or has not emerged yet (not yet).

Scores are calculated by summing individual responses (yes=10, sometimes=5, and not yet=0) for each of the five developmental domains. As each domain include six questions, the maximum raw score for each is 60. The cutoff score is two standard deviations (SD) bellow the mean of the reference group in any developmental area.

In contrast to previous versions, for the ASQ-3 children whose scores fall between one and two SD below the mean are included in the "monitoring zone". This means that they should be rescreened at regular intervals, and provided with follow-up activities for practicing skills in the specified domains (Squires et al., 2009).



#### Validation

#### Main findings

The ASQ has been found to be an effective screening tool for developmental delay. In general, the ASQ has shown good psychometric properties in terms of validity, reliability, sensitivity, and specificity (Mackin et al., 2017: Singh, Yeh, & Blanchard, 2017: Squires et al., 2009: Velikonja et al., 2016). Table 2 summarizes the findings from the most comprehensive study developed to date (Squires et al., 2009), in which the properties of the ASQ-3 were examined using a sample of 18,572 cases.

Table 2. Psychometric properties of the ASQ-3 in the original study (Squires et al., 2009)

Sample size	18,572
Age (in months)	1-66
	- Internal consistency: poor to good(Cronbach's alpha= .5187)
	- Interobserver reliability: 93% agreement between parents and trained
Reliability	examiners (ICC= .4369)
	- Test-retest: 92% agreement between parents' first and second
	administration (ICC= .7582).
	- Specificity > 75% in all age groups
Malialia.	- Sensitivity > 80% in all age groups
Validity	- False positive ranges from 8.7% (2-12 months) to 22.1% (14-24 months)
	- False negative ranges from 10.8% (14-24 months) to 17.5% (42-60 months)

#### Validation in other countries

Although the instruments were developed in the United States, they have been translated and adapted to other contexts and languages. Specifically, the last edition (ASQ-3) has been validated in numerous countries such as Portugal (Lopes, Graça, Teixeira, Serrano, & Squires, 2015), Chile (Schonhaut, Armijo, Schönstedt, Alvarez, & Cordero, 2013), and Brazil (Filgueiras, Pires, Maissonette, & Landeira-Fernandez, 2013), with overall positive results.

#### Advantages

- In contrast with other tools (e.g., the Bayley Scales) the ASQ questionnaires don't require a trained professional for administration. They can be completed by parents and caregivers in the home setting (the reading level ranges from fourth to sixth grade, ensuring parental comprehension, Squires et al., 2009).
- The ASQ-3 is a relatively brief screen measure, thus, completion time is short (between 10 and 15 minutes).
- Being parent/caregiver-completed tools, the ASQ questionnaires constitute a cost-effective alternative to provider-administered screening tools.

These aspects are important because some of the barriers cited by clinicians frustrating the use of standardized tools are time constraints, lack of staff to perform screening, and a lack of reimbursement for completing developmental screening tools (Morelli et al., 2014).



#### Limitations

- Variations in age versions used result in heterogeneous evidence (Velikonja et al., 2016).
- Some studies have reported the tendency of ASQ-3 to identify more children at risk than other equivalent screeners (such as the Bayley scales), resulting in low predictive values (Schonhaut et al., 2013). This limitation was reported in previous studies using the second version of the questionnaires (ASQ-2, Gollenberg, Lynch, Jackson, McGuinness, & Msall, 2010).
- A recent study reported the inability of the ASQ-3 to detect less severe cases of motor developmental delay, resulting in reduce discriminatory accuracy of the ASQ-3 motor areas
- found that the discriminatory accuracy of the ASQ-3 motor areas (King Dowling et al., 2015). Because of this limitation, the authors of the study discourage the use of these questionnaires for screening of motor delays in children aged 3.5-5.5 years.
- A recent systematic review of the psychometric properties of the ASQ-3 showed that the
  reliability, sensitivity, and specificity of the translated/adapted versions were lower compared to
  the original questionnaires (Velikonja et al., 2016). This was especially true for more culturally
  specific domains such as the personal-social and problem-solving subscales (see also Filgueiras
  et al., 2013).



# Ages and Stages Questionnaires: Social Emotional (ASQ:SE-2)

#### Background and purpose of the questionnaires

The Ages and Stages Questionnaires: Social Emotional (ASQ: SE) were developed by Jane Squires, Diane Bricker, and Elizabeth Twombly and published in 2002. The revisions of these questionnaires started in 2009 and the second edition was released in 2015 (Squires, Bricker, & Twombly, 2015). Revisions for these questionnaires were based on 16,424 questionnaires that included data from 14,074 children in the United States.

The ASQ: SE are parent-completed screening tools to identify young children at risk for social-emotional problems who may require further evaluation. These tools can be used alone, or in conjunction with the ASQ, or any other developmental measure.

Table 3. Main characteristics of the Ages and Stages Questionnaire: Social Emotional, 2nd Edition

Measure name and acronym	The Ages and Stages Questionnaire: Social Emotional, 2 <sup>nd</sup> Edition
	(ASQ: SE-2)
Audience	Parents/ caregivers
Target age group	1 to 72 months
Number of questionnaires	9 (age intervals include 2, 6, 12, 18, 24, 30, 36, 48, and 60 months)
# of items	19-33 (depending on the version)
Areas assessed	Self-regulation, compliance, communication, adaptation, autonomy,
	affect, and interaction with people
Administration time	10-20 minutes (depending on the version)

#### Validation

#### Main findings

The ASQ: SE and the ASQ: SE-2 have been found to be reliable (both in terms of internal consistency and test-retest correlation). Overall sensitivity and specificity were .81 and .84, respectively, satisficing the criteria of 70%-80% for each (American Academy of Pediatrics, 2001).

A recent systematic review of twenty-four socio-emotional screening instruments for young children (10 and under) concluded that the ASQ:SE show above-average measurement psychometric properties (McRae & Brown, 2017). Similarly, another systematic review of 18 parent-report measures of social-emotional development in infants and toddlers revealed that the ASQ-SE-2 was one of the most comprehensive and psychometrically sound measures currently available (Pontoppidan, Niss, Pejtersen, Julian, & Væver, 2017).

#### *Validation in other countries*

Studies conducted in other countries show that the reliability and sensitivity of the translated/adapted versions were lower compared to the original questionnaires (Velikonja et al., 2016)



Table 4. Psychometric properties of the ASQ: SE-2 in the original study (Squires et al., 2015)

Sample size	14,074 children
Age (in months)	1-72
Reliability	<ul> <li>Internal consistency: fair to excellent (Cronbach's alpha= .7190), with an overall alpha of .84</li> <li>Test-retest: 89% agreement between parents' first and second administration (ICC= .91 across intervals).</li> </ul>
Validity	<ul> <li>Specificity ranges from 76.2% (18 months) to 98% (60 months)</li> <li>Sensitivity ranges from 77.8% (2 months) to 84% (24 months)</li> <li>False positive ranges from 2.0% (60 months) to 23.8% (18 months)</li> <li>False negative ranges from 16% (24 months) to 22.2% (2 months)</li> </ul>

#### Limitations

- The ASQ: SE versions are designed for very young children only (up to 6 years; see Mcrae & Brown [2017] for a review of socio-emotional screening instruments for children ages 10 and younger).
- Most of the psychometric information is available through technical reports and not through peer-reviewed journal articles.
- A recent systematic review of the psychometric properties of the ASQ-3 and ASQ: SE showed that the reliability and sensitivity of the translated/adapted versions were lower compared to the original questionnaires (Velikonja et al., 2016).



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# Children's Mental Health Crisis Planning: Final Results from a Needs Assessment of Seven lowa Counties

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## **Executive Summary**

Francis Lauer Youth Services, a Youth & Shelter Services (YSS) organization, contracted the Center for Social and Behavioral Research (CSBR) at the University of Northern Iowa to conduct a needs assessment for children's mental health in North Central Iowa.

The primary goal of the needs assessment was to analyze the perceptions and needs of key stakeholders, current recipients (children and families), and community members with regard to mental health in children in this area. To meet this goal, a mixed methods design was implemented involving two phases:

- 1) Phase 1 consisted of 22 in-depth qualitative interviews with stakeholders and three focus groups of parents and youth; and
- 2) Phase 2 utilized a quantitative telephone survey and a qualitative validation focus group of parents from the targeted area.

Below is a summary of the key findings from Phase 1, distinguished between in-depth interviews and focus groups:

### Main themes that emerged across the in-depth interviews:

- The number of young children with serious mental health conditions has increased in recent years.
- Family structure and circumstances are viewed as playing a major role in children's mental health.
- There is no shared/common definition of mental health "crisis."
- There is a lack of comprehensive training on children's mental health.
- Scarcity of services/providers, long waiting times, and transportation barriers are significant obstacles to accessing mental health care for children.
- There is significant need for greater coordination and communication across sectors.
- Schools play a central role in identifying early warning signs of children's mental health conditions.
- There is a need to develop and implement protocols to assist and refer children in crisis.
- [Among those working in the juvenile justice system] There is a growing concern about negative impacts of placing children with mental health conditions in the juvenile justice system.

#### Main themes that emerged across focus groups:

- More accessible mental health care is needed for children.
- Waiting times are a critical barrier to successful crisis stabilization.
- The lack of providers who attend to and screen young children limits treatment options.
- The cost of mental health care services and coverage limits of insurance policies prevent access.
  - There is significant need for better collaboration and coordination among providers and agencies.
  - Parents face significant challenges in obtaining diagnoses and treatment for young children.
  - Parents need support to counter their frustration, helplessness, and sense of isolation.



- Mental health challenges (their own or others') are a central part of life for many youth.
- Friends play a major role in supporting one another emotionally.
- Youth express some ambivalent attitudes towards mental health, but stigma is still a barrier to help-seeking.
- Family support and involvement is important for youth.

The following are key findings that emerged from the Phase 2 quantitative telephone survey of parents and associated validation focus group with parents:

- Parents feel more knowledgeable about their children's physical health than they do about their children's mental health.
- The majority of parents see evidence of mental health conditions in children as stable or increasing over the last five years.
- Most parents interviewed know or have had personal experiences with mental health conditions in children.
- Parents perceive a lack of community resources for children with mental health issues.
- Parents have limited knowledge of mental health resources in the community.
- Stigma is a significant concern.
- Respondents report that they would turn to primary care providers if they had questions about their children's mental health, or if their children had a mental health condition.
- Scarcity of providers, distance to services, and cost of services are seen as key obstacles to accessing mental health care for children.
- Most participants are satisfied with the services and treatment that their child received, but see increased accessibility to healthcare as needed.

For the qualitative aspects of Phase 1 and 2, it is important to note that focus groups and in-depth interviews represent the views and perceptions of only those who participated. These may not be representative of these groups in the general population even in the 7-county area of interest. Additionally, the sample of parents used in the second phase telephone interviews was drawn from a targeted list of parents to increase efficiency and may not fully represent the entire/broader population of parents in this area. Finally, because the survey targeted a subgroup of the population (parents of young children), the data presented are not weighted to any broader population parameters.



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## Introduction

The purpose of this study is to better understand the needs for mental health crisis services in children 12 and under in North Central Iowa. There is a scarcity of data surrounding children's mental healthcare services and the mental health challenges facing youth and their families in this area of Iowa. To close this gap, Youth and Shelter Services, Inc. (henceforth YSS), a nonprofit organization that provides education, treatment, and residential services to children, youth, and families, contracted with the Center for Social and Behavioral Research (CSBR) at the University of Northern Iowa to conduct a needs assessment of seven counties (Cerro Gordo, Chickasaw, Floyd, Hancock, Mitchell, Winnebago, and Worth) in North Central Iowa. Organizations use needs assessments to determine priorities, make improvements, and/or allocate resources. It involves identifying the needs or "gaps" between the current state or conditions and the desired outcomes or "wants."

As part of its planning grant proposal to the Iowa Department of Human Services, Francis Lauer Youth Services – a YSS organization and the project's lead entity – is developing a children's mental health crisis services plan for these seven counties in Iowa. Aligning its focus with the Iowa Department of Human Services (DHS) 2015 Children's Mental Health Study Report, YSS has identified several potential gaps in providing mental health services to youth in the seven county area (DHS, 2015):

- Lack of collaboration among providers;
- Lack of a system of care to ensure coordinated services;
- Lack of clear definitions of what constitutes a crisis, what it means to have a mental health condition, and what it means to be stabilized;
- Lack of places to refer children and concerns about how quickly services can be accessed;
- Lack of services for children ages 6-12 who are in crisis;
- Need for crisis services for children who do not meet hospitalization criteria or for whom inpatient care is not available;
- Families feel helpless and hopeless when seeking services for their child's mental health condition and they think psychiatric medical institutions for children (PMIC) is the only option;
- Lack of awareness by families of services currently available;
- Lack of transportation to services providers; and
- Need for therapeutic schools and classrooms.

To assess whether these gaps were shared by stakeholders and likely recipients of the mental health crisis services plan, a mixed-method design was developed (see Figure 1), involving two phases:

- Phase 1 focused on key stakeholders and current or potential recipients of mental health services. Twenty-two in-depth qualitative interviews with community stakeholders (i.e., law enforcement personnel, justice system professionals, primary care providers, mental health providers, educators, school administrators, and other community partners) were conducted to better understand their views and experiences. Additionally, three focus groups with a total of 5



parents and 15 youth were held to learn more about the perspectives of those who are recipients of services or might have needs that the new or expanded services might target.

- Phase 2 focused on parents from the targeted area and incorporated a quantitative telephone survey of 258 parents/guardians and a validation qualitative focus group of 7 parents of children twelve and under. The interviews and focus group explored attitudes toward mental health in children, their perceptions about potential barriers to seeking help, and their self-assessment of knowledge about mental health conditions and services in the area.

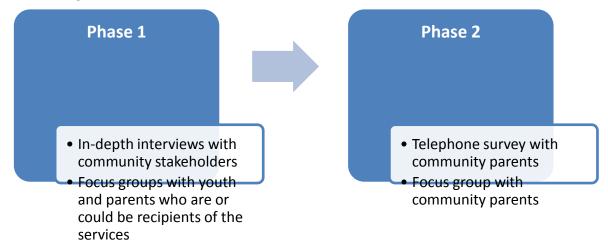


Figure 1. Design of the needs assessment

In this report we synthesize the needs identified and offer recommendations for consideration for next steps. We also present a logic model that was developed by YSS, with assistance from CSBR. Table 1 reflects the activities completed by CSBR across the project timeline. The structure of the report follows the timeline described in Table 1, presenting Phase 1 results first, followed by the logic model, and Phase 2 results. General conclusions and recommendations are presented at the end of this report. Finally, summaries of methodologies and instruments used in the needs assessment are included in the appendices.

Month **Specific activities** Nov. Dec. Jan. Feb. Mar. Apr. May Jun. Oct. 16 16 17 17 16 17 17 17 17 In-depth interviews Phase 1 Focus groups Analysis and reporting Logic Model Working group meetings Telephone surveys Phase 2 Focus group Analysis and reporting

Table 1. Timeline of needs assessment activities



Note: Colored cells indicate activity in progress.



## **Phase 1 Overview**

The needs assessment utilizes a mixed-methods sequential exploratory design and includes qualitative and quantitative components to determine the community perceptions of those needs and gaps and to identify other needs that may not have been previously identified. This first section of the report focuses on which gaps or needs emerged from the qualitative data collection, that is, from in-depth interviews with key informants and focus groups with parents and youth.



## **Phase 1 Findings**

## **Section 1: Perspectives of Key Informants (KI)**

The people who are likely to have a direct relationship with the recipients of the mental health crisis services plan are an important constituency to include as part of a needs assessment. For the purposes of this study, the concerns from key sectors of the seven communities were captured via qualitative indepth interviews with key informants from law enforcement, the juvenile justice system, education, mental health care, primary care, and other community partners. These individuals shared their perceptions, experiences, and beliefs regarding children with serious mental health conditions, and eleven themes emerged from the analysis. The following section explores each of these themes in turn with added context and illustrative quotes.

# KI 1: The number of young children with serious mental health conditions has increased in recent years.

There was considerable agreement that serious mental health problems in children have increased in recent years. This perception was shared by almost all informants, regardless of their occupation or the county in which they work. Several informants mentioned the increasing number of serious mental health conditions that now appear at younger ages. A school administrator shared her experience in this regard:

It was [previously] rare for me to see 4 and 5-year-olds with serious stuff. It's not rare for me to see that [now]. It was rare for me to see a 9-year-old suicidal. It's not rare for me to see that now.

School administrator.

Notably, beyond perceiving an increase in the <u>number</u> of younger children with serious mental health conditions, many informants detected an increase in the severity of the conditions.

## KI 2: Family structure and circumstances are viewed as playing a major role in children's mental health.

Different aspects related to family structure and circumstances emerged in almost all the interviews as a perceived key explanatory factor for increasing serious mental health conditions in young children. Some informants mentioned discipline-related issues, especially the lack of clear and consistent boundaries. Reference was also made to the changes in family structures after divorces, and the repercussions they can have on children. Difficulty accessing financial resources and meeting the needs of children was identified as an important factor by some participants.

Sometimes it might be family resources and not being able to get basic needs met.

Sometimes it's inability to access resources in the community because maybe it's a rural setting or they don't have the funds or the gas or the transportation to access [care].

- AEA staff member.



Besides of the lack of economic resources, several informants mentioned the lack of time spent with children and the difficulties in balancing work and family responsibilities. As this school administrator stated:

Both parents are working. They may be working different hours and it's just hard for them always to give the detailed time to their kids.

- School administrator.

Informants also mentioned parent experiences that can often have an indirect, negative effect on children, such as parents own mental health conditions, drug abuse, or domestic violence. As one judge noted:

The parents have unresolved mental health issues, the grandparents have unresolved mental health issues, and then it's just a multi-generational issue [...] so it's difficult to then engage all those people to address this child's needs because they aren't capable of dealing with their own.

- Judge.

Some of these factors also emerged when informants discussed contributors to positive and negative outcomes. In this regard, the achievement of positive results was linked to family engagement. Across the groups there was consensus regarding the importance of engagement in achieving consistent attendance at the appointments and follow-through on treatment recommendations. In addition, some informants mentioned that the establishment of clear limits and routines in the family setting helps to achieve positive results. This included cases in which children transitioned from a residential facility to home, as one school administrator noted:

When they [the children][...] transition back home if families haven't developed a different way of responding or interacting or communicating then pretty soon you're right back where you started again.

School administrator.

When discussing factors that lead to negative outcomes, key informants also highlighted inconsistent participation in treatment and family settings with limited structure and discipline.

#### KI 3: There is no shared or common definition of mental health "crisis."

A number of symptoms were often used to define a crisis situation, including suicidal ideation, recurring thoughts about life and death, self-harm, or violent behavior. However, a consistent definition of mental health crisis in children did not emerge.

Beyond symptoms, several Informants established certain criteria that would serve to identify a situation as critical. Many of them pointed to a situation featuring a loss of control where the child is not able to stabilize him or herself, jeopardizing his or her safety or that of others. Unlike this description, which refers to a specific point in time, several school administrators defined a crisis as an incapacity to function properly in the school setting.



Besides the diversity of views to defining a mental health crisis, many informants stressed the subjective component involved in identifying these situations. As one school administrator explained:

What might be a crisis for one family or for one student might not be a big issue for another family or another student [...] it's a matter of perspective and individual experiences.

- School administrator.

### KI 4: There is a lack of comprehensive training on children's mental health.

Among the different groups, there was a strong sense that more training is needed to better assist children and their families. Participants gave examples of the type of content they consider most necessary, including aspects related to child development and to mental health conditions. Another salient issue, especially among justice system professionals and law enforcement, was the need for training to be more applied in nature. As one interviewee noted:

I don't think we get that kind of information that would be helpful in actually dealing face-to-face with parents and kids that have those issues.

- Judge.

Similarly, some informants pointed out that training should be oriented towards educating individuals about the resources available in their community. As this primary care provider indicated, the professionals who work with children are not always aware of the options available:

I won't lie, there's lots of probably resources and community things that are out in my own community that I'm not even aware of as a provider.

Primary care provider.

In this regard, various informants across sectors and locations pointed out the utility of making available to professionals and agencies a list of key services organized by area.

## KI 5: Scarcity of services/providers, long waiting times, and transportation barriers are significant obstacles to accessing mental health care for children.

When explaining the factors that contribute to negative outcomes, many informants mentioned a lack of access to adequate care. Some of them attributed this situation to the lack of sufficient community resources, leading to long waiting lists. Others pointed to economic constraints and transportation barriers, particularly affecting this group, as children this young cannot drive and depend completely on others to get around and receive the treatment they need.

Although many informants recognized that the quality of services has improved in recent years, there was a strong sense that the resources available are not enough, particularly in rural areas. As one interviewee indicated, this situation is limiting access to services, as parents must have the time and money to travel:

I work in rural Iowa, Chickasaw and Fayette County, and certainly we lack resources like you would see in Des Moines, Cedar Rapids, Waterloo, and there's times that travel and all that stuff is difficult for parents.



Court officer.

The lack of resources locally and transportation barriers also emerged in the parent focus group as major obstacles to assistance. In addition, many informants expressed regret that most services are aimed only at adolescents, further limiting the options for children.

The most requested services were related to crisis stabilization for young children. Some, like this primary care provider, argued that immediate access to a qualified provider who can assess the severity of the crisis must be a priority:

We need to have immediate access to an assessment of the child's safety so you can decide whether the child can be managed at home or whether they need to be in a facility for a brief period of time until things stabilize.

- Primary care provider.

Across the different groups, long waiting lists were considered a fundamental barrier to meeting the needs of children in crisis and preventing the situation from getting worse. For example, one interviewee working in juvenile justice described the significant delays in getting prompt care even in very serious cases:

It's not uncommon that we have a suicidal child, they go to the hospital, they have a hearing three days later, and they get released with an appointment with a counselor that will be in four weeks.

- Judge.

Additionally, several Informants stressed the need to increase placement options and make available to families short-term locations to receive help other than the hospital.

According to the key informants, the professionals most in demand were counselors, psychologists, psychiatrists, and social workers. This gap was viewd as more acute in rural, compared to urban settings, as this quote from a judge working in a rural area illustrates:

There's really two places in town to get psychiatric or psychological care and they have a huge backlog. Most of them do not specialize in children. A lot of those who do specialize in children work part-time [...] so we simply don't have enough individual counselors available.

- Judge.

#### KI 6: Many providers do not feel comfortable diagnosing young children.

Among some providers, there was a perception that other providers are not comfortable diagnosing and treating young children. As one mental health provider pointed out:

A lot of people just don't agree to see kids. They'll say [they assist] nobody under the age of 18, or nobody under the age of 15, or whatever it is.

Mental health provider.



The reasons explained for this reluctance to assess and provide care to this population were lack of specific training for this age group, wariness to prescribe medication to children, and legal concerns. One mental health administrator expanded on this last point:

Psychiatrists are very nervous about all the work that it takes to see kids and they're also nervous about litigation and they don't want to get pulled into court as a witness for a case, all those kind of things apply.

Mental health administrator.

This difficulty in finding providers to assess and treat young children was echoed among parents in the focus group described later in this report.

### KI 7: There is a significant need for greater coordination and communication across sectors.

The importance of increasing communication and collaboration between sectors was highlighted, as informants provided suggestions as to how those collaborations could be helpful to patients and their families. Regarding services, many informants expressed the view that inter-agency collaboration positively impacts the care given. Some, like one administrator at a mental health facility, cited the need to share information to avoid the duplication of services:

I think that it's important [...] that we don't put parents through the same process time and time again. So if you have one evaluation, you should have one evaluation and that should be shared with parents' consent so that the parents don't have to go through three or four different evaluations for different agencies for different funding purposes.

- Mental health administrator.

Not only was collaboration and communication across sectors considered a factor in achieving positive results, a lack of collaboration and communication was considered a contributing factor to negative outcomes. As one interviewee noted:

[Silos] can lead to duplication of services so families can be overburdened anyway with multiple appointments per week, per every two weeks, and then if there's not coordination among those agencies, then certain services can be duplicated which I think leads to exhaustion for the family but also might lessen the effectiveness of interventions.

- Mental health administrator.

Across counties, informants agreed that communication between groups is very limited. This situation has a negative impact on children, making it difficult to coordinate services. As one school administrator noted:

An example of that would be when a child is hospitalized for a mental health issue and they transition back to school. Often times we have no idea how to help them, or that they've been hospitalized.

School administrator.

This lack of communication between groups also undermines the referral process, as this school social worker explained:



Sometimes there are questions about not knowing who to send things to. I might have the name of the agency, but I'm not quite sure to whose attention I should send it, or how I get a release signed, or where the release is, and that type of thing.

AEA staff member.

In addition to confusion on the provider side, lack of communication and collaboration can be bewildering for parents. Informants noted the importance of service provider teamwork, ability to build rapport with children, and ability to provide families with support and guidance. One informant working in the juvenile justice system emphasized the importance of this last point given the sense of powerlessness many parents/guardians experience:

A lot of parents, they just don't know what to do and they've been trying to do it on their own for a year or two or sometimes even longer and they don't know what the next step is and they're scared and they don't know what is going to happen and how they're going to make it work.

Judge.

In this regard, several health providers noted the value of parent groups in providing support and guidance to families. In this same sector - primary and mental health providers - some participants expressed the need for there to be a professional figure who could act as a single point of contact for the family, following up with them and coordinating services. As one mental health provider explained:

If there was a key point person to get everyone involved and handled each case [...] that would be overwhelming but also it would provide that contact with all the different agencies.

- Mental health provider.

Although all interviewees stressed the importance of constructing a collaborative network, some of them underscored the difficulties of placing this approach into practice. These difficulties were related to the organization of the mental health system, as this provider pointed out:

We are all silent within mental health because we get paid in different ways and we get paid from different sources [...]. So, in order for all of us to fulfill our mission, we get siloed just naturally because one level of care will get paid by the state or another level of care will get paid by the Medicaid or the NCOs. Another level might get paid by a grant. So the very nature of the way the mental health system is set up silos us and it makes much more difficult to have a seamless kind of continuum of care which is a problem.

- Mental health provider.

### KI 8: Schools play a central role in identifying early warning signs.

Across the groups, informants highlighted the importance of schools in identifying early warning signs of potential mental health conditions. The number of hours they spend with the children, along with their experience, means that teachers are seen as key figures for this task. As one elementary school administrator noted:

Parents may not always be able to see something as significant at home. They know it as their normal. But what we see in a classroom of twenty students may show significant



discrepancies and so it's our job to have those conversations and to seek out those services.

School administrator.

However, some school staff exhibited resistance to carrying out this task, either due to a lack of training, or because they think it is beyond the appropriate scope of their job. Another middle school administrator explained:

Some [teachers] are just very fearful to even try to begin to approach that and so they [...] don't go there. There is others, I think, that don't believe it's their job to address those issues that that's somebody else's job in another field. And then I think there's some that are very willing they just don't necessarily have the skills yet to recognize signs.

School administrator.

Nevertheless, one mental health counselor promoted the idea of empowering educators to not only identify, but also to intervene. According to this informant, educators could coach parents on validating their children, and engage in a conversation with parents, children, and other teachers on noticing changes in child behavior. This approach could serve as a first line of defense against mental health conditions in children, thus freeing up some of the burden currently placed on mental health providers.

I'm suggesting that it is not just early identification by the school, but early intervention by the school. So to know that as a faculty I don't need to have to be a mental health professional to be able to kind of coach a parent on validating a child or coach, I mean, I'm able to do and I can be empowered to do some of those things that a patient doesn't necessarily need to be referred to a mental health provider for those things.

- Mental health provider.

Also advocating for an increased role among schools, some school staff members suggested implementing therapeutic support programs that would integrate therapy and education within the same setting. For instance, one administrator focusing on special education explained:

My dream, my ideal would be that we have programs in place where we have almost like a therapeutic setting where we have [...] some students that are being educationally served in a setting where we have therapists there on a daily basis that that's an integral part of the services that they are receiving at school.

School administrator.

## KI 9: There is a need to develop and implement protocols to assist and refer children in crisis.

Although many informants recognized the existence of internal procedures at their agencies, they all indicated that there existed no formal protocol indicating how to address mental health crises in children. Others, like this AEA staff member, stated that if they exist, they are not being applied:

There's not a system that I have seen at any of the districts that I've worked that are widespread. If it's on paper, it's not widespread in reality.

AEA staff member.



Despite this, some informants, especially among the education sector, reported that filling that void was an important task to better assist these children. As one school administrator noted:

At school a really well-written and well-implemented behavior intervention plan can have great, great effects for kids.

- School administrator.

In contrast, one judge indicated that what is needed is not the development of a protocol, but rather having staff that can properly implement it:

I think the procedures and mechanisms are there in the court system. I don't think the providers are there in the communities.

Judge.

## KI 10: There is a growing concern about negative impacts of placing children with mental health conditions in the juvenile justice system.

One of the issues that emerged among judges and law enforcement was the overrepresentation of children with mental disorders in the juvenile justice system. As noted by one judge, the number of cases is so high that, by default, juveniles are treated as if all had mental health conditions:

It's just so common for juvenile cases that we kind of treat them all as if the children probably do have mental health issues.

Judge.

According to some Informants, like this court officer, this situation is the result of the lack of accessible and appropriate resources:

Just because a kid is self-mutilating or suicidal doesn't mean they're a criminal and delinquent [...] it's just like an adult, some of those cases are [...] mental health cases but yet it seems like nobody knows what to do with these kids or adults, and then they end up in our jails and prisons and [...] I think it's the same with young kids, even 12 and under.

Court officer.

One law enforcement officer explained how criminal charges, although sometimes necessary, can have long term negative consequences for children with mental health condition:

Sometimes they [criminal charges] can be a detriment as far as just having that hanging over their head whatever it might be. Let's say that there was a serious assault with an injury or something that can, just because of the nature of the whole situation can negatively impact the whole ongoing process.

Law enforcement officer.



## Section 2: Perspectives of Parents (P) and Youth (Y)

Phase 1 of the needs assessment also obtained information via focus groups with members of the population intended to be served by the mental health crisis service plan developed by YSS. To this end, three focus groups were conducted: one group of parents, and two focus groups with youth. Each group offered a unique perspective whether as a parent of a child with mental health care needs or as a youth from the North Central lowa area.

Section 2 presents the themes that emerged from the parent focus group and youth focus groups, respectively, with analysis findings and selected quotes organized by parent (P) and youth (Y) themes.

Parent focus group findings reflected four over-arching themes.

## P 1: More accessibility to care is needed to address scarcity of services, transportation barriers, waiting times, and lack of evening and weekend hours.

Three primary barriers to access to care emerged from the analysis of the parent focus group: waiting times, lack of screening for young children, and the cost of the services.

#### *P 1.1:* Waiting times are a critical barrier to successful crisis stabilization.

In the parent focus group, waiting times emerged as a key barrier to treatment access. The unmet need for more mental health providers results in long wait times for appointments and increased travel distance to existing providers. In addition, parents described several examples of the multiple visits to various providers that were required before finding a place and/or provider and/or treatment that worked for their child. One parent, in response to trying to get an appointment with a child psychiatrist, stated:

They're full in Iowa. You need to get a child psychiatrist? Yeah, there's only seven in Iowa. You won't see them for months. There's none in North Iowa for a child, you know? Closest one, I think, is Waterloo/Cedar Falls and they work out of Des Moines.

- Parent

Waiting times are compounded when children are in crisis and immediate attention is crucial. As one parent explained, even half an hour is a long time in such situations. In another example:

It's the waiting. To get into residential it's two to three months, you know? By the time you get in there, we were in crisis several times and my one son, who couldn't come home because it wasn't safe, since there was no hospitals open in lowa. I had to turn [him] over to foster care and ... they were able to keep him there for three weeks until he could go into residential.

- Parent



The lack of professionals also affects the distance parents must travel in order to access resources. As this parent indicated:

We drive hours each way to go to where we need to go.

-Parent.

## *P 1.2: The lack of providers who attend to and screen young children limits treatment options.*

Parents conveyed a sense of desperation due to the shortage of providers and services for young children, and identified the provider shortage as an acute barrier to addressing their child's mental health needs especially when crisis stabilization was needed. Parents reported situations where their child was not diagnosed with a mental health condition, because the child was very young and current practice limited the ability of providers to diagnose until after a specified age. Consequently, without a diagnosis, treatment options were limited or not available to them. This is reflected in this parent's experience:

You can't diagnose a child at that age with ADHD until they're in school. I'm like he needed something then.

-Parent.

Another parent described how, after getting an appointment with a psychiatrist, her child was they told they would not be seen because the provider did not see children under age 10.

There was a consensus among parents that having more professionals who are easy to access would be a very important step forward. As one parent explained: "professionals usually don't work at night or weekends," such that, if there is a crisis, the options are limited. Also mentioned was the need to have more inpatient resources, specialized daycare for children with mental health care needs, and respite care.

*P 1.3:* The cost of mental health care services and coverage limits of insurance policies prevent access. Parents also identified the cost of services and treatment restrictions in insurance coverage as obstacles to treatment. As one parent explained:

We had to stop going to the psychiatrist because we couldn't afford it. It was costing us \$120 some dollars a week to go there.

- Parent.

However, the cost of services is not the only limitation in this regard, and restrictions on insurance coverage were also mentioned. As this same participant explained, having insurance does not guarantee access to services:

We have insurance, but insurance doesn't cover [expletive].

- Parent.



# P 2: Significant need for better collaboration and coordination among providers and agencies.

A lack of collaboration between professionals and across sectors hampers delivery of quality care for a young child with mental health care needs. Parents described a lack of collaboration across the multiple professionals and sectors from whom they seek treatment, services, or referral. These factors included a lack of communication and care coordination between providers. For example, a parent explained how at an agency one of the psychiatrists who treated her son during the week had changed his medication without talking to the psychiatrist who treated him during the weekend, causing confusion and disappointment. Other parents described a lack of collaboration in the school setting, where administrators may be trained in techniques for helping children with mental health care needs, but classroom educators or para-professionals may not. In addition, a few parents reported the perception that their school did not want to readmit their child after being elsewhere for a time.

## P 3: Parents face significant challenges obtaining diagnoses and treatment for young children.

Just as providers acknowledged significant difficulties diagnosing and treating young children, parents recognized this too. Parents described differential diagnoses and changes in treatment as an obstacle to achieving successful treatment. Parents expressed frustration with continuous changes in treatment, whether it was a change in the professionals caring for their child(ren) or the medications prescribed. In the context of medication, changes are viewed with wariness, especially when professionals propose them without knowing their child's case in depth. As one parent explained:

His [son's] first prescription was Ritalin and that really wasn't working so [...] after that, we went to a psychiatrist in Iowa City [...] we walked in, he talked to [his son], I don't even know if it was 10 minutes, called me in, said, well, let's just change his medicines to Adderall. How did he know just this is what we had to do in 10 minutes?
- Parent.

Other parents shared examples of how constant changes are negative for their child(ren). "My [child] had a new therapist once a month," echoed one parent. In another example, a parent described a meeting with school personnel on whether to transfer her child, when someone supported her view that the change would be detrimental:

She has never met us, never met [son], and she pipes up and says, 'it seems to me if one of his biggest issues is structure, what good would it do for him to go from one school to another to then go to another?' She goes, that doesn't make sense to me which that's what I was saying too.

- Parent.

### P 4: Parents need support to counter their frustration, helplessness, and sense of isolation.

Parents expressed a profound sense of frustration, helplessness, and sense of isolation in trying to meet the mental health care needs of their child(ren). Parents described the heavy burden to how much space is consumed in their daily lives searching for options and answers. Parents identified getting support as a



vital factor that contributes to positive outcomes. This was the first sentiment that was expressed when respondents were asked about the most challenging part of parenting at the start of the focus group. The response, "Not getting the support you need when you need it in a crisis." was voiced spontaneously and strongly even before more specific questions were asked about obstacles or barriers.

It cannot be understated how much parents' appreciate and value the collaboration across agencies and sectors (e.g. education, day care) when it is realized. Parents' described occasional situations where they felt a sense of collaboration, and how that impacted them. For example, one parent was very satisfied with her child's new Special Ed teacher, who took the extra step to explore resources to use with her son:

She went out and she was able to find YouTube videos and she researched and she went back to me and told me, you know, I researched and I found ways, and that made me feel so good because she was one of the first people to actually care.

- Parent

Another parent was very positive about her experience with her child's school. In particular, her child's therapist attended a meeting at the school, which made her feel supported and credible in the requests she was making.

This view takes on special importance for those parents who have experienced the feeling of constant attack. As this participant explained:

[Talking about the school staff] they don't necessarily mean to attack you and maybe they do, but sometimes you feel like they're coming at you.
-Parent.

Youth focus group findings reflected four over-arching themes.

#### Y 1: Mental health challenges (their own or others') are a central part of life for many youth.

In one of the youth focus groups, several teens described personal experiences where their own or others' mental health challenges were a central part of their life. A few reported having been diagnosed with a mental health condition and noted the significant challenges they faced dealing with those conditions. Others described the mental health challenges of extended family members and the impact it has had on their own family.

Several youth told of times when they themselves or people close to them had helped their friends, and they felt a strong sense of responsibility to be there in times of need. The following quote revealed how much "space" mental health concerns took up in daily life:

I always get the friends that say that they have depression and that they're suicidal and such and that kind of affects me because I'm always very self-conscious of where my phone is, if it goes off and especially at night, and I don't sleep if I see that they're having difficulties with something during the day and they might need me so I'm sitting up



staring at my phone like, come on, you need me, I'm ready for you, I've been researching that, I got you.

- Youth

This theme was more subtle in the other focus group. One youth described keeping emotions bottled up:

[M]ine starts out with me getting aggravated at somebody....it just gets bottled up and it turns into like stress...then it just turns into something bigger.

- Youth

## Y 2: Friends play a major role in supporting one another emotionally.

Most adolescents from the youth focus groups agreed that they would first turn to close friends if they or their friends needed help. Some of them also mentioned family members, especially when they were very close to them. Other figures, such as teachers or law enforcement officers, were mentioned, but in the latter case, prompted some reticence:

Would you want to like talk to a cop if you're about to like hurt yourself? Would you want to communicate with authority? [...] I'd prefer to talk to a friend or family.

- Youth

As one teen indicated, the person to whom you turn changes, but the common denominator is that he or she is "someone that you trust."

To find information about mental health, participants from both youth groups expressed that they mainly turned to friends and family members. Doctors were also mentioned, as well as the Internet. However, the participant who mentioned this last source raised concerns about reliability, stating that:

You can't trust, you can't believe everything that's on it.

-Youth

# Y 3: Youth express some ambivalent attitudes towards mental health, but stigma is still a barrier to help-seeking.

Focus group discussions revealed a certain ambivalence in youth's attitudes towards mental health. On the one hand, the first answers received in the group of high school students were related to the false self-diagnosis of mental illnesses. That is, the observation that some students attributed to themselves various conditions when, in reality, no such diagnosis had been made. This observed behavior noted by several of the respondents suggests that wearing the label of a mental condition may have some perceived value for some students.

However, youth in both groups also recognized the existence of stigma around mental health issues, and suggested that stigma can become a barrier to seeking help. In one of the groups, when indicating to whom they spoke about emotional well-being, there was a consensus that they tended to keep it to



themselves. Various participants explained this attitude citing fear of "getting bullied," "getting labeled," and in general, the fear of "people judging them."

One participant explained that this fear changed over time -- at first she did not want to share her diagnosis, but now she is not as hesitant to do so.

## Y 4: Family support and involvement is important for youth.

In both youth focus groups, the last question that was asked was a general question, "If you could say one thing that you would have liked others to know about teens and children going through a hard time, what would it be?" Notably, in both groups, youth responses focused on advice for parents even though the question was not framed toward parents. Collectively, the sentiments reflected a strong desire for parents to be involved, but a caution it should be on their [the youth's] terms. Youth encouraged parents to talk with their children, with insightful advice to "listen with eyes open" to be able to look for warning signs of struggles that might be occurring. When asked what words teens use to describe someone going through a hard time, they used phrases such as "struggling," "feeling lost," "in an abyss." As one student noted, "Sometimes it's not what they [the youth] say, it's what they do." Another student explained it this way:

Don't just brush it off because of how they word it because sometimes they don't really know how to tell you something's wrong and they'll try and explain it to you but they may say it in a way that makes it seem like oh, it's not that big of a deal. You should really listen to the words the say.

-Youth

Conversations reflected a certain ambivalence in youth's expectations of their parents. On the one hand, they want them to be involved, but at the same time, the youth expressed a desire for a specific approach. For example, there was interest in knowing about their own parents' experiences as children/youth and the way the parents handled those challenges. However, this desire was tempered with advice to not assume that what worked for the parent will necessarily work for the child. As one youth pointed out:

"Maybe your child is going through the same thing that you did and you may know what will happen, but the child isn't gonna think of it the same way that you did and they're probably, like possibly not going to end up in the same place that you did at the exact same time and the exact same place. They aren't you. It's not like they're going to become you if they do what you said to do. It may have worked for you but it may not work for them."

- Youth.

Youth wanted parents to be honest with them, and recognition that mental health challenges are difficult and real. They also wanted parents to keep listening, without assuming they know everything about the situation, because "kids don't always tell their parents everything."



Above all, youth were emphatic with one bit of advice: "Don't ignore it." They explained that when teens are going through a hard time, they want to be heard, but may not be able to express it clearly or fully in one conversation, or with words alone. As a student explained about their plea to parents, "You don't need to talk, you just need to listen to my problems. Let them [YOUR TEENS] vent to you."



## Phase 1 Conclusions

In their proposal for the planning grant, YSS aligned their focus with a 2015 lowa Department of Human Services report regarding children's mental health. In doing so, they identified several gaps in services within North Central lowa (DHS, 2015). In this section, these gaps are compared to the themes that emerged from the in-depth interviews and focus groups.

Below are the areas in which gaps identified by YSS <u>were also identified and corroborated by key</u> informants **and** parents:

- Lack of services for children ages 6 to 12 who are in crisis.
- Lack of collaboration among providers.
- Lack of a system of care to ensure coordinated services.
- Concerns about how quickly services can be accessed.
- Need for crisis services for children who do not meet hospitalization criteria, or for whom inpatient care is not available.
- Lack of easy access to service providers (e.g., transportation, distance).

<u>Key informants</u> working with children echoed several of the areas identified by YSS. These included:

- Lack of clear definitions of "crisis" or what constitutes a crisis.
- Lack of places/providers to which/whom children can be referred.
- Need for therapeutic schools and classrooms (note: this need mentioned only by some informants in the education sector and was not always referred to as "therapeutic school" or "therapeutic classroom").

One gap identified by YSS that did not fully emerge in the parent focus group was:

• Families feel helpless and hopeless when seeking services for their child's mental health condition and they think psychiatric medical institutions for children (PMIC) is the only option.

While families did express significant feelings of helplessness and hopelessness around the issue of seeking services and treatment for their child's mental health condition, they did not express any specific views that psychiatric medical institutions for children (PMIC) were their only option. Given the strong preference for in-home assistance, this may reflect a negative view about PMIC as a first line of care and help or may simply reflect a lack of knowledge about PMICs. Although some parents did have experience with residential care for their children, they did not express the view that this was the only option.

There was one area in Phase 1 in which identified gaps were not echoed by either key informants, parents, or youth: that is, lack of awareness by families of services currently available. In this phase of the needs assessment, it is likely that the parent group participating in the early focus group was much



more knowledgeable than other parents might be. For key informants, many expressed a concern about lack of coordination, communication and more challenges about access to the services available. Youth tended to believe they know what to do even if those approaches may not be deemed by experts and other providers as the most appropriate in any given crisis situation.

Although several of the following have been noted as issues in numerous discussions by various members of the project planning committee, the following themes emerged from the in-depth interviews and focus groups <u>but were not previously chosen for inclusion in the list of gaps previously</u> identified for focus by YSS:

- Key informants, parents, and youth all mentioned the disadvantages and challenges that occur when they switch providers and feel like they start from the beginning with each new provider.
- Both key informants and parents identified the importance and value of supporting parents to achieve positive outcomes.
- Key informants highlighted the need for more training, and the importance of schools in identifying early warning signs.
- Key informants emphasized the need to develop and implement protocols to assist and refer children in crisis.
- Youth considered friends and family members as their main sources of emotional support and information about mental health.

Taken together, this summary comparison indicates that the original gaps identified by YSS were indeed worthy of attention as evidenced by the corroborating sentiments and insights offered by those participating in the in-depth interviews. This overlap provides validation for the direction outlined by YSS. However, these findings are specific to individuals that are familiar with mental health services in the area. For this reason, Phase 2 focuses on parents from the targeted geographic area, in order to gather a more comprehensive view of the perceptions and needs of children's mental health in the 7-county area.



## **Phase 1 Recommendations**

The recommendations included in this section are suggested areas of special focus/consideration by the Children's Mental Health Crisis Planning Work Group. These recommendations are based on the qualitative findings of the in-depth interviews.

#### Recommendations for activities are:

- Fully develop crisis stabilization services for children twelve and under.
- Develop and test system to improve communication between and among families, schools, agencies and professionals.
- Develop information sources that are easily accessible to direct parents and professions to available children's mental health services. Consider having provider information organized by area with special attention to rural locations.
- Provide child-specific crisis stabilization and referral training to professionals across all sectors included in this report.
- Maintain and expand support groups for parents.
- Explore the feasibility of implementing therapeutic support programs or therapeutic classrooms in school settings.
- Provide regular parental skill training (e.g., Nurtured Heart) to families throughout the 7-county area.
- Consider introducing a position that would coordinate care across different providers and acts as a single point of contact for families.
- Encourage and support professionals across sectors to develop and implement protocols for crisis situations arising in children and teens.
- Lead community efforts to increase the number of professionals and services to treat children's mental health conditions.
- Consider development of a children's mental health awareness campaign targeting parents (e.g., how to recognize signs/symptoms of serious mental health issues and how to listen and talk to kids).



## **Logic Model**

As the planning work progressed, the CSBR evaluators encouraged the planning group to consider developing a logic model as a tool to structure and guide the project – to help make visible the various activities and desired outcomes. Over the course of three planning work group meetings, CSBR assisted the planning group in developing a logic model. Logic models are visual representations of project components, connecting planned resources, activities, outputs, and outcomes (see Figure 2). This tool is commonly used in program design, implementation, and evaluation (Knowlton & Phillips, 2009).



Figure 2. Typical components of a logic model

The main components of a logic model are briefly summarized below:

- **Inputs** refer to any kind of existing resource (e.g., human, financial, community, infrastructure) secured or in place to support or allow implementation of the activities.
- Activities describe the specific actions, tasks or interventions planned to achieve the desired goals.
- **Outputs** are the expected tangible results derived from or created by activities.
- **Outcomes** represent specific changes in participants, organizations, and community members resulting from program implementation.

Although logic models are dynamic, living documents that are updated throughout the course of a project, the most recent version of this project's logic model (as of 6/8/2017) is presented in Figure 3 (following page).

This model not only helped the group identify key project components, but was also useful in developing and charging subcommittees responsible for different dimensions of the projects. Currently, seven subcommittees have been formed around the following topic areas: data metrics and indicators, screening and assessment, staffing and training, therapeutic classrooms, awareness and marketing, post-service protocol, and infrastructure planning.



Inputs	Activities	Quitauto	Out	namas
iliputs	Activities	Outputs	Short-term Out	comes Long-term
Investment in technology for web	Organize a planning group and facility ate regular meetings	Final plan for addressing gaps in children's / youth MH crisis stabilization	Decrease the interval between discharge and first	Decrease number of children experiencing
based interaction	Conduct a community needs assessment related to children's / youth MH crisis stabilization	Report(s) of needs assessment findings	follow-up service	(re)traumatization
Financial and time investments by FL and	Coordinate with YSS to identify CARF requirements and develop plan for implementation	CARF Implementation Plan	Increase in the number of instructional minutes for both children and	Decrease the number of children involved with DHS and JCO
community partners  Expertise and	Gather information on successful designs used elsewhere (Shelter?)	Summary of key features of successful designs	adolescents	Reduction in the % of
experience of FL and	Review and select sources of existing data for monitoring	New measurements for outcomes	Increase the % of parents	adolescents presenting to the
community partners/professionals	Review and add key variables for intake and exit process	New intake/exit forms	(participating in services) who perceive they are	ED with a crisis who are admitted to the psychiatric
Evaluation expertise	Review, select, train and implement a common screening tool for use by FL crisis team members	Screening results used for referral	better able to help their child	unit (where beds are available)
and experience of UNI CSBR partners	Review, select, train and implement a common assessment tool for use by FL mental health providers	Assessment results used for treatment by FL staff	Decrease the number of	Reduction in the number of children presenting at the ED with a crisis
	Design and name the family shelter	Shelter named and communicated	children needing PMIC care	with a crisis
	Complete any necessary remodeling and landscaping (Shelter)	Structure remodeling/landscape in place	Increase the % of youth who perceive they are able to	Reduction in repeat visits to the ED related to MH by
	Develop a coordinated care process in consultation with other stakeholders	Coordinated care process plan/report	manage their MH issues most of the time	individual children
	Gather information and provide a summary of therapeutic classrooms	Summary report of therapeutic classrooms		Increase the number of mental health services available for
	Recruit, hire, and train shelter staff	Shelter staff in place		children
	Recruit, hire, and train staff for the Mobile Crisis Team	Mobile Crisis Team in place		Decrease the incidence of future crisis (among those who
	Recruit, hire, and train community-based Mobile Crisis Team staff for in-home follow-ups/ongoing support	Community-based staff in place		have received services)
	Determine and obtain appropriate licensure	Licenses obtained		Increase the number of non- hospital referred youth
	Secure paneling for clinicians	Clinicians paneling documented		receiving services within 5
Figure 3:	Develop program manuals to guide implementation	Program implementation manuals		days
Beginning logic model	Develop-post service protocol	Post-service protocol plan		Decrease the number of
	Develop a formal marketing plan	Marketing plan		weekly in-home crisis incidents reported by parents
	Administer youth and narent nerceived self-efficacy measures for	Parent/vouth ratings of perceived self-		participating in stabilization



## Phase 2 Overview

This section of the report focuses on the information gained in the second phase of the project, that is, from the telephone survey of parents in the seven-county area plus a focus group of parents in Charles City (See Appendices for details on methodology). The sample of parents for the survey came from a targeted (non-probability) list of households from the geographic area of interest. Because focus groups are qualitative in nature and include only a small number of respondents, the findings represent the views and thoughts of those who participated. While the findings are valuable for the purposes of the needs assessment and the time and resources available, the findings should not be used as the basis for generalizing to the entire population of parents with children in the targeted age group in this geographic area of Iowa because of the limitations of the telephone sample frame and qualitative purpose of the focus group. The results reported in the figures and tables reflect percentages rounded to the nearest whole percent unless otherwise noted. Percentages may not sum to 100% due to rounding to the nearest whole number. Furthermore, for uncued open-ended questions, percentages are not reported.



## **Phase 2 Findings**

Parents are one of the primary target groups in the second phase of the needs assessment. Telephone interviews and a focus group of parents were used to capture experiences with, perceptions of, and beliefs and attitudes about children with serious mental health conditions. Awareness of services for mental health treatment in the area was also explored. The following sections present the main findings from these Phase 2 efforts.

## Parents feel more knowledgeable about their children's physical health, than they do about their mental health

In this section, we compare parents' perceptions regarding the physical and mental health of their children. As can be seen in Figure 4, the parents felt more knowledgeable about their children's physical health: while eight out of ten parents (80%) felt somewhat or very knowledgeable about their children's physical health, only five out of ten (52%) said the same about their children's mental health.

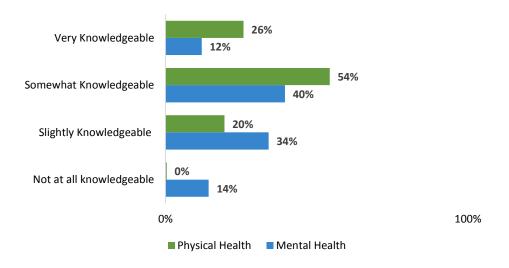


Figure 3. Perceived knowledge of physical versus mental health

This finding was echoed in the focus group conducted with parents. As noted by one of the participants:

I feel not as knowledgeable, especially compared to [...] physical health and activities and things, nowhere near as knowledgeable.

Another participant shared a similar feeling:

I feel like I have the knowledge, you know, if my kids needed food I would know where to get that or if they needed other things I would know where to get that, but I wouldn't even know where to start to get them mental health help.

In an uncued question, parents were asked what came to mind when they thought of mental health in young children. The most common type of response that emerged was how parent behaviors can have a direct impact on the mental health of their children. Many parents discussed the ways in which children are raised (e.g. showing affection, teaching what is right and wrong, setting a good example) and how a



child's home environment (e.g., a feeling of safety, supportive atmosphere for the child, financial stability) play a major role in a child's overall mental health. Parents also noted the lack of resources available in treating mental health conditions among young children. Additionally, many parents mentioned specific disorders, such as depression, ADHD, and anxiety.

# The majority of parents see mental health conditions in children as stable or increasing over the last five years

Most parents believe that the number of children with mental health conditions in their communities has risen (44%) or remained stable (38%) over the last 5 years (Figure 5). There was a non-trivial proportion of "Don't know" answers to this question, which suggests that parents are not especially familiar with this issue.

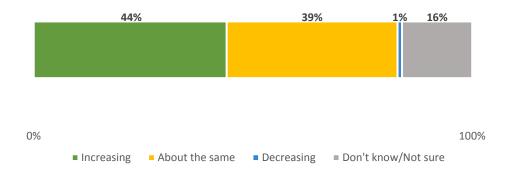


Figure 4. Perceptions of trends in children's mental health

# Most participants report knowing or having had personal experiences with mental health conditions in children

Most respondents reported that they know children with serious mental health conditions (90%). A third of them have known children ages 3 or younger in this situation, and more than 50% indicated that they have known children ages 5 or younger who have mental health conditions (see Figure 6).

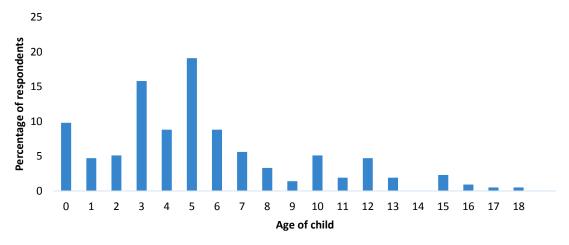




Figure 5. Age of the youngest child with serious mental health conditions that respondents know

When asked (in an uncued question) what they would do if their child experienced a mental health crisis, the most common type of response was contacting a medical professional. This included seeking help from pediatricians, family care providers, nurse practitioners, and, in some cases, going to the emergency room. Many parents also suggested getting in touch with a mental health professional (e.g., psychiatrist, psychologist, therapist, or counselor). Interestingly, a sizeable number of parents noted that they would handle the situation by simply talking with their child.

Around one third of the parents (32%) reported that they had contacted someone about their child's mental health. When asked in an uncued question who they contacted, parents reported having turned to mental health providers, primary care providers, counselors, therapists, and school officials.

Of those who had contacted someone, slightly over half (55%) said that their child(ren) had been diagnosed with a mental health condition (Figure 7). Almost all of these children who had been diagnosed (96%) had also received some kind of treatment according to parent reports. The most common option was outpatient treatment alone (79%), or outpatient treatment along with another type of treatment (16%).

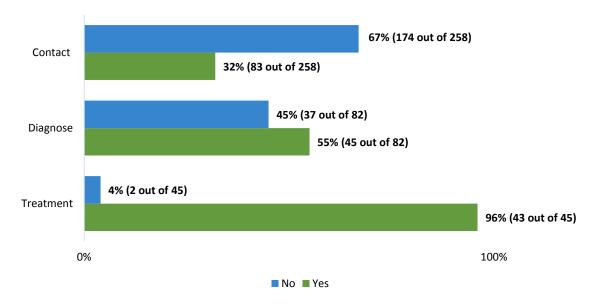


Figure 6. Percent of respondents who have contacted an agency regarding their children's mental health, whose children have been diagnosed and have received treatment

#### Perceptions of and experiences with mental health crises

In an uncued question, respondents described what they consider a mental health crisis. Consistent with themes that emerged during in-depth interviews and focus groups with stakeholders (Phase 1 of the needs assessment), they described behaviors like self-harm and harming others. Also, similar to the stakeholders, they cited the inability to function in everyday life. Additionally, they mentioned other



symptoms such as anxiety and depression, behavioral changes, lack of emotional control, and/or disruptive behavior. Mentioned to a lesser extent was the inability to focus and eating and sleeping disorders.

As shown in Figure 8, about two out of ten respondents (19%) indicated that their child (or children) has experienced what they consider a mental health crisis. In most cases (72%) the crises have arisen on more than one occasion (Figure 9), ranging from 2 (23%) to 76 or more times (14%). As indicated in Figure 10, a quarter of these children had their first crisis at age 5 or younger (26%), and almost half when they were younger than 10 (49%).

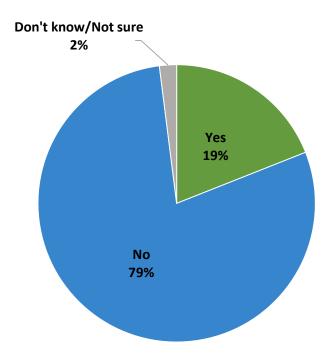


Figure 7. Proportion of parents who reported having a child who experienced a mental health crisis



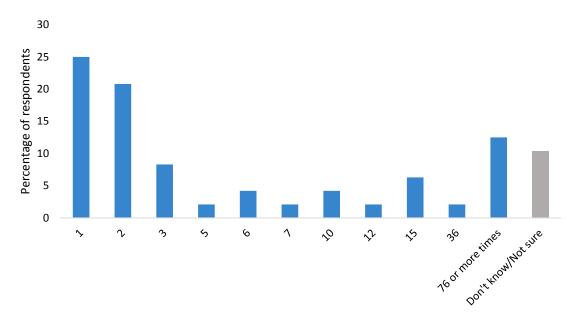


Figure 8. Number of times crises have occurred

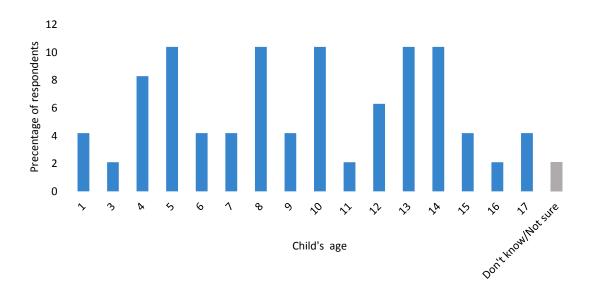


Figure 9. Child's age when the first crisis occurred

Among those who reported having a child who had experienced a self-described mental health crisis, parents were asked, in an uncued question, what was done to stabilize their child during the first crisis. The most common response among these parents was communicating with their child (e.g., listening,



talking, calming them down). Other parents reported contacting a mental health specialist and/or a doctor.

Parents of a child who had experienced more than one self-described mental health crisis were also asked what was done to stabilize their child during the most recent crisis. Again, communication with their child was the most common approach to stabilization, followed by seeking help from a mental health specialist.

#### Parents perceive a lack of resources for children with mental health issues

When evaluating the resources for young children available in their communities, differences were also evident (Figure 11). While a quarter of respondents (24%) believed that the resources available for physical health are less than needed, this percentage rose to over 50% when considering resources available for mental health (56%).

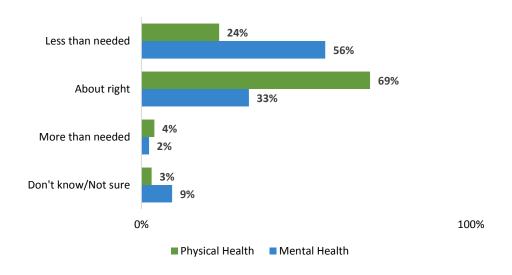


Figure 10. Perceived need for services in the community

Parents in the focus group also mentioned that the resources available for mental health are not enough, especially for young children. As this participant stated:

There are very few specialized in pediatrics and even then it's usually providers will see 13 on up but not the little [ones]... Its very hard to get them seen.

#### Parents have limited knowledge of resources

As indicated previously, almost half the parents did not feel knowledgeable about their children's mental health. Relatedly, in Figure 12 we see that almost a third (30%) reported that they were not at all familiar with the services in their communities for children with mental health conditions.



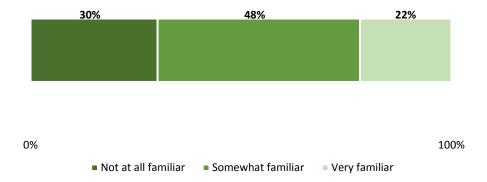


Figure 11. Familiarity with mental health services for children

Similarly, as indicated in Figure 13, only one third of participants (33%) reported having heard of the Nurtured Heart Approach (NHA), a support and teaching approach designed for parents whose children have mental health conditions (Ahmann, 2014).

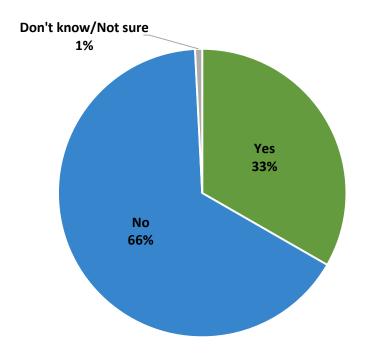


Figure 12. Familiarity with the Nurtured Heart Approach

In addition, for around a third of parents (31%) who have not contacted any agency regarding their children's mental health, they indicated that they thought finding professional help (if it was needed) would be difficult (Figure 14). They saw the main reasons for this difficulty as the lack of resources and providers in the area, and not knowing where to go.



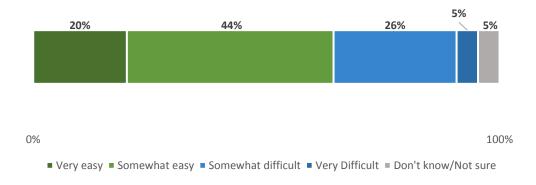


Figure 13. Perceptions of difficulty finding professional help

#### Stigma is a significant concern

Parents also provided responses that show that the stigma surrounding mental health discourages them from speaking openly about this subject (Figure 15). Just a small minority of the respondents (8%) indicated that parents are not concerned about what others may think or say when talking about mental health. In contrast, almost six out of ten (57%) stated that parents are somewhat or very concerned about this issue.

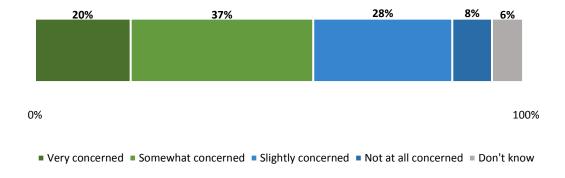


Figure 14. Parent's concern about what others may think or say when talking about children's mental health

The existence of stigma is also reflected in other indicators (Figure 16). For example, 40% of the respondents agreed that most people look down on children who visit a counselor for emotional or behavioral reasons. Additionally, about two thirds of those surveyed (61%) disagreed that most children would be happy to hang out with someone who has emotional or behavioral problems.



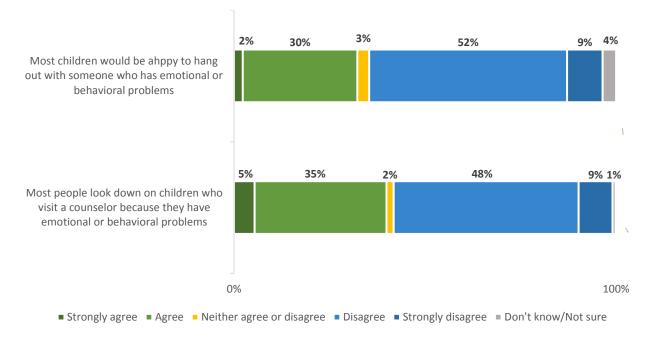


Figure 15. Attitudes toward children with mental health issues

In an uncued question, parents were asked about the biggest fears or worries that parents would have if their child was diagnosed with a mental health condition. The most common response to this item was stigma. Parents noted their concerns with their child being singled out, made fun of, or ignored by their peers or adults.

Concerns about mental health stigma and possible parental blame also emerged in the focus group. The following quote reveals a parent's concern about being blamed for their children's mental health conditions:

If someone is sick with diabetes, you wouldn't hide that, and people would be aware of that, but with the mental health or even if it's with your kids too, you don't want other parents to judge you or your parenting, like you're doing something wrong so your kid has an issue so people are a lot quieter about it, I feel like.

Along the same lines, another participant explained how stigma can prevent people from seeking help:

I feel like if I would have been in school and I was like, oh, that person is seeing a therapist, there must be something wrong with them [...] People are going to look down on you because [you see a counselor].

Respondents would turn to primary care providers if they had questions about their children's mental health, or if their children had a mental health condition

If they had questions or concerns about their child's mental health, the vast majority of parents indicated that they would turn to their pediatricians or primary care providers (81%). Slightly less than a quarter reported that they would consult school officials (23%) or mental health providers (21%), while some would talk to friends or family members (8%) or do research on the Internet (5%).



In the event their children had a mental health condition, the providers they would turn to are, in this order: primary care providers, school officials, and mental health providers. As was the case when they sought to gather information, respondents would again rely on informal sources of information such as friends or family members and their religious social network.

# Scarcity of providers, distance to services, and cost of services are seen as obstacles to accessing mental health care for children

Three-quarters of respondents (75%) specified at least one obstacle that would prevent them from seeking help if their child was diagnosed with a mental health condition (Figure 17). The most cited barriers were the cost of the services (32%), the lack of providers in the area (28%), insurance restrictions (14%), distance to mental health services (11%), and stigma (11%). One in four respondents (25%) reported no barriers to seeking treatment.

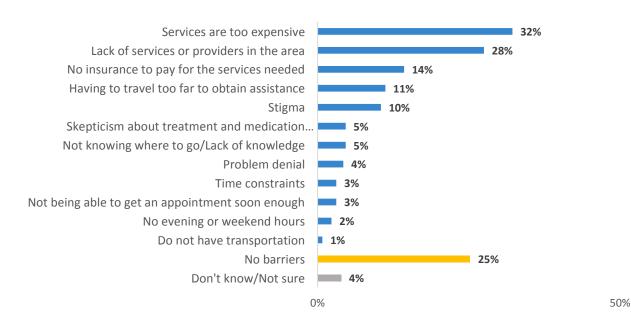


Figure 16. Potential barriers for treatment seeking

# Most participants are satisfied with the mental health services and treatment that their child received, but see more accessibility to healthcare as needed

In general, parents of children who have received mental health treatment reported being satisfied (44%) or very satisfied (35%) with the services received. However, around 20% felt dissatisfied or very dissatisfied (Figure 18).

When asked in an uncued question what worked best, parents reported therapy, counseling, and medication. They also cited finding the right provider, mentioning their specialization in the treatment of children.



In contrast, the most common complaint was the lack of access to care due to the lack of local services, the waiting times, and the limited insurance coverage for mental health treatment. Other aspects mentioned by respondents were the secondary effects of medication, and not seeing progress in their children's recovery.

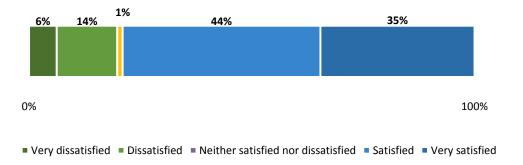


Figure 17. Satisfaction with the services and the treatment received

Respondents' main recommendation to improve the process they went through was to render the services more accessible by including a greater number of providers and resources in the community. They also mentioned the need to bolster awareness of mental health conditions and the services available, give providers more training, and increase communication between agencies and providers.

#### **Areas of improvement**

To identify potential areas of improvement, we asked respondents what suggestions they would make if they were designing a system of mental health services for their communities. For them, the main areas to be improved would be, in this order:

- Improved accessibility to mental health services
- Providing education and information to the community
- Creating support groups for parents and children
- Helping parents accept the situation, and
- Combating stigma

To a lesser extent, they also indicated that they would improve coordination and communication among agencies, and give providers more training.

In an uncued question, parents were asked what schools should do to assist children with mental health conditions. The most common type of response was related to school counseling. That is, schools should continue to employ school counselors, employ more qualified counselors, and allow outside mental health professionals into the schools when necessary. Many parents also noted the importance of communication between schools and parents so that both parties were working together to provide coordinated care for the child. More broadly, parents also suggested special accommodations (e.g., special classrooms, one-to-one instructions, and specialized programs for children with mental health conditions) and more training for teachers and staff.



#### Phase 2 Conclusions

In the proposal for their planning grant, YSS aligned their focus with a 2015 lowa Department of Human Services report regarding children's mental health. Several gaps in services within North Central lowa were identified (DHS, 2015). In this section, these gaps are compared to the findings from the telephone interviews and the focus group.

Below are the areas identified by YSS that were affirmed in the findings of the second phase of data collection:

- Lack of services for children ages 6 to 12 who are in crisis.
- Lack of easy access to service providers (e.g., transportation, distance).
- Concerns about how quickly services can be accessed.
- Lack of clear definitions of "crisis" or what constitutes a crisis.

There were some gaps identified by YSS that did not emerge in the second phase of data collection. However, these gaps are very specific to providers, children in crises, and their families and, therefore, less likely to emerge among parents from the broader community in this geographic area. These gaps include:

- Lack of a system of care to ensure coordinated services.
- Need for crisis services for children who do not meet hospitalization criteria, or for whom inpatient care is not available.
- Lack of places/providers to which/whom children can be referred.
- Need for therapeutic schools and classrooms
- Families feel helpless and hopeless when seeking services for their child's mental health condition and they think psychiatric medical institutions for children (PMIC) is the only option.
- Lack of collaboration among providers.

Finally, there were gaps identified in the second phase that were not highlighted by YSS in the aforementioned report:

- Lack of information regarding resources available for mental health treatment in children.
- Lack of knowledge regarding mental health conditions in children.
- Need to reduce stigma about mental health conditions in children.

Taken together, there was overlap between the gaps identified by YSS and those recognized by parents from the seven county area. This confirmation along with the findings from phase one (qualitative data collection among stakeholders and service users) provides further validation for the direction outlined by the organization.



### **Phase 2 Recommendations**

The recommendations in this section are put forth for consideration by the Children's Mental Health Crisis Planning Work Group. The recommendations are based on the second phase of data collection, which included telephone interviews and a focus group with general population parents.

#### Consistent with recommendations from Phase 1:

- Consider development of a children's mental health awareness campaign targeting parents (e.g., how to recognize signs/symptoms of serious mental health issues and how to listen and talk to kids).
- Develop easily accessible information sources for available children's mental health services and providers organized by area.
- Develop and test a system to improve communication between and among families, schools, agencies and professionals.
- Lead community efforts to increase the number of professionals and services to treat children's mental health conditions.
- Maintain and expand support groups for parents of children with mental health conditions. New recommendations based on findings from Phase 2:
  - Increase prevention services/efforts (e.g., advocating for regular mental health check-ups with providers).
  - Work to reduce stigma toward mental health conditions through educational and social marketing campaigns where possible.



## General conclusions and recommendations

The main purpose of the table presenting conclusions and recommendations below is to inform the work of the planning group in developing and expanding the current mental health services for children. In order to compare the gaps identified by YSS with the findings from the needs assessment, we present two tables. Table 2 depicts overlapping gaps between YSS and the different groups participating in the needs assessment. As can be seen below, all needs singled out by YSS were also recognized by at least one of the targeted groups. In most cases, these needs were echoed by two or more of these groups.

Table 2. Comparison of the gaps identified by YSS with those identified by community stakeholders, service recipients, and parents

Gap identified by YSS	Key informants	Youth	Parents of service recipients	General parents
Lack of collaboration among providers				
Lack of a system of care to ensure coordinated services				
Lack of clear definitions of what constitutes a crisis,				
what it means to have a mental health condition, and				
what it means to be stabilized				
Lack of places to refer children				
Concerns about how quickly services can be accessed				
Lack of services for children ages 6-12 who are in crisis				
Need for crisis services for children who do not meet				
hospitalization criteria or for whom inpatient care is				
not available				
Families feel helpless and hopeless when seeking				
services for their child's mental health condition and				
they think psychiatric medical institutions for children				
(PMIC) is the only option				
Lack of awareness by families of services currently				
available				
Lack of easy access to service providers (e.g.,				
transportation, distance)				
Need for therapeutic schools and classrooms				

Note: Dark blue represents fully overlapped, whereas light blue represents partial overlap.

Similarly, Table 3 portrays gaps that were not identified by YSS, but emerged as key findings either in Phase 1, Phase 2, or both.



Table 3. Additional gaps identified by study participants

Gap	Key informants	Youth	Parents of service recipients	General parents
Lack of information regarding resources available for				
mental health treatment in children				
Lack of knowledge regarding mental health conditions				
in children				
Need to reduce stigma about mental health conditions				
in children				
Need to develop and implement protocols to assist and				
refer children in crisis				
Need for more training for providers				
Lack of support for parents of children with mental				
health conditions				
Lack of continuity when switching providers				

Note: Dark blue represents fully overlapped, whereas light blue represents partial overlap.

Considering these findings, we suggest the following for consideration:

- Fully develop crisis stabilization services for children twelve and under.
- Develop and test systems to improve communication between and among families, schools, agencies and professionals.
- Develop easily accessible information sources for available children's mental health services and providers organized by area which special attention to rural locations.
- Provide child-specific crisis stabilization and referral training to professionals across sectors.
- Maintain and expand support groups for parents.
- Explore the feasibility of implementing therapeutic support programs or therapeutic classrooms in school settings.
- Provide regular parental skill training (e.g., Nurtured Heart) to families throughout the 7-county area.
- Consider introducing a position that would coordinate care across different providers and acts as a single point of contact for families.
- Encourage and support professionals across sectors to develop and implement protocols for crisis situations arising in children and teens.
- Lead community efforts to increase the number of professionals and services to treat children's mental health conditions.
- Consider development of a children's mental health awareness campaign targeting parents (e.g., how to recognize signs/symptoms of serious mental health issues and how to listen and talk to kids).



- Increase prevention services/efforts (e.g., advocating for regular mental health check-ups with providers).
- Work to reduce stigma toward mental health conditions through educational and social marketing campaigns where possible.

# **Appendix A: Phase 1 Methods**

## **Study Design**

Two modes of qualitative data collection were used for the first phase of the needs assessment. First, semi-structured, in-depth interviews with key providers and stakeholders from different professions were used to explore perceptions and views surrounding mental health crisis stabilization in young children aged 12 years and under. Key informants working in professions that interact and assist this population were targeted, including law enforcement personnel, justice system professionals, primary care providers, mental health providers, educators, school administrators, and other community partners. In-depth interviews are one way to obtain detailed information about a program or service, thus offering a more complete picture of what the perceived gaps may be and possible ways to close those gaps.

The second mode of qualitative data collection utilized focus groups with parents and youth, aged 13 to 18 years, to explore their personal experiences and insights surrounding the mental health care needs for children and their families in North Central Iowa. The themes and key issues that emerge from focus groups can provide valuable information from the users of mental health care services and inform the needs assessment with the unique perspectives from the population intended to be served. In addition, both the in-depth interviews and focus groups can provide substantive information that is valuable to the development of a quantitative questionnaire used in a survey for the second phase of the needs assessment.

#### Recruitment

Participants for the in-depth interviews were recruited by email invitation from a list of key informants compiled by the Planning Committee. In cases where an email address was not known, CSBR staff searched for work numbers associated with potential respondents. Following the first round of email invitations and phone calls, additional follow-up phone calls were used to recruit participants for the key informant interviews.

Three focus groups were arranged through YSS, and included one group of parents, and two focus groups with youth. Participants in the three groups included parents of a child(ren) under 12 who had been or were currently receiving mental health services (n=5), students who attended an alternative high school (n=8), and students attending YSS Day Programs (n=7), respectively. Focus group participants received a \$20 gift card per person to compensate them for their time.

#### **Materials**

For the in-depth interviews, a semi-structured interview guide tailored for each group was developed with input from the Planning Committee to elicit information about the unique mental health care



needs posed by youth aged 12 years and under, the availability of services and local resources, the quality/efficacy of those resources where available, and the specific areas of service gaps (e.g., interventions, respite, shelters) for serving this population. The interview guides contained approximately 23 to 48 questions, respectively, and probes were included to explore topics thoroughly and to facilitate meaningful conversation (guides are available upon request).

For the focus groups, the moderator guides focused on the views and experiences of parents toward mental health care services for children, youth perceptions of mental health in day-to-day life, opinions about sources of information and resources for mental health concerns, views on available and needed health care services for children and youth in crisis, and perspectives on how to best help youth with mental health care needs and their families. The moderator guides contained between 15 and 29 questions, respectively (guides are available upon request).

The topics covered in the interviews and focus groups are described in Table 4.

Table 4. Main topics covered in the interviews

Technique	Key topics covered
In-depth interviews	Incidence of mental health conditions in children
	Factors related to mental health conditions in children
	Definition of crisis
	Factors related to positive and negative outcomes
	Characterizations and gaps with training
	Perceptions of available resources
	Role of agencies in crisis stabilization
	Perspectives about current practices and protocols
Parent focus group	Crisis identification and intervention
	Health care access, use and barriers
	Effective and ineffective responses to children and families in crisis
Youth focus groups	Definition of mental health and mental health crisis
	Knowledge and sources of information about mental health
	Barriers to the use of mental health services
	Effective and ineffective responses to youth with mental health concerns

#### **Data Collection**

A total of 22 key informant interviews were conducted by telephone between December 3<sup>rd</sup>, 2016 and February 1<sup>st</sup>, 2017. The in-depth interviews were conducted by Neal Pollock or Mary Losch, while Eva Aizpurua listened and took field notes. The average interview length was 34 minutes.

The focus groups took place at a local alternative high school and at YSS facilities on January 19<sup>th</sup> and January 20<sup>th</sup>, 2017. All three focus groups were moderated by Mary Losch, while Erin Heiden and Eva Aizpurua took field notes. The focus groups ranged from 45 to 75 minutes in length.



The interviews for both the in-depth interviews and focus groups were audio-recorded with the participants' consent and transcribed verbatim for use in analysis. The focus groups were not designed as research – they were solely to support the evaluation and needs assessment. However, informed consent was obtained from all participants prior to conducting the interview by verbal consent via telephone for the in-depth interviews and in-person for the focus groups. The in-depth interview study was submitted for research review and was approved by the Institutional Review Board at the University of Northern Iowa.

## **Analysis**

The transcripts were analyzed using qualitative content analysis designed to reduce or distill the content in order to identify emergent themes that can be meaningfully interpreted – paying special attention to context in which the data were collected (Roller & Lavrakas, 2015). This type of analysis focuses on the underlying and contextual meaning of what was reported in the in-depth interviews and focus groups. The analysis used a combination of deductive and inductive coding (also called "hybrid" coding, e.g., Fereday & Muir-Cochrane 2006). The deductive codes were generated in part from the specific topics of interest that were utilized in the interview guides. The inductive codes emerged from the content of the interviews and focus groups. The codes are then grouped and synthesized into (more general) categories, which in turn are aggregated into more general themes and concepts arising from within and across interview responses. The transcripts for the in-depth interviews and the focus groups were coded by staff members. The code system (and the categories and themes that were developed on the basis of the coding process) was developed gradually and collaboratively among them.

#### Limitations

It is important to note that findings are based on qualitative interviews with a small number of individuals and are not generalizable. There may be implied measurement properties of qualitative data when descriptions such as "most", "several", or "a few" are used. However, this is not an appropriate interpretation of qualitative findings. The authors aimed to be mindful when using these descriptive qualifiers, so as not to imply a quantitative assumption about the findings. In all cases, descriptions such as "most" or "a few" simply mean the view or perspective was not unanimous (i.e. it was neither held by "none" nor "all"). Caution should be used to avoid inferring a quantitative inference from statements that use these descriptions.

A second limitation is that all youth focus group participants were subgroups of larger youth populations – one at an alternative high school and another in a restricted day group setting. Their views and experiences are likely different from youth in more traditional education settings. It is possible that these young people may be more familiar with mental health conditions themselves or in close friends/peers than would be true for other youth in general and if so, our analysis and findings might have been amplified because of this.

# **Participant Profile**

Table 5 and Table 6 summarize the demographic profiles of the participants of the in-depth interviews and focus groups, respectively.



Table 5. Demographic profile of in-depth interview participants

Characteristics	n
Sex	
Female	13
Male	9
Key informant group	
Law enforcement	4
Court	3
Primary care providers	2
Mental health providers and administrators	6
Educators and school administrators	6
Community partners	1
County*	
Cerro Gordo	14
Chickasaw	1
Floyd	2
Hancock	3
Mitchell	2
Winnebago	2
Worth	1

<sup>\*</sup>Note: Some interviewees split their time in multiple counties; therefore, the total number of counties does not match the total number of interviewees.

Table 6. Demographic profile of focus group participants

	Parent	Youth focus group	Youth focus group
Characteristics	focus group	1	2
Sex			
Female	4	7	0
Male	1	1	7
Age range (youth only)	n/a	16-18 years	13-17 years
Age range of child(ren) needing			
mental health services (parents only)	9-12 ½ years	n/a	n/a

<sup>\*</sup>Note: Information on self-report of race and ethnicity was not collected.



## **In-Depth Interview Guides**

### **Interviewer Guide: Community Partners**

Please tell me a little bit about what you (and your agency) do related to mental health needs of children?

What, if any, role do you have in identifying or referring children in need of mental health crisis stabilization?

Is this work part of an organization or agency?

In your experience, have the number of children under 12 with these types of mental health issues been increasing, decreasing, or are they about the same over the last 3-5 years?

[Probe] What thoughts do you have about the factors that may be contributing to the [Increase/Decrease] in mental health disorders in children under 12 years of age?

[If the same] In your view, what are some of the contributing factors to mental health issues in children under 12 years of age?

In your experience, what are some factors that contribute to positive outcomes when treating children with mental health problems?

[Probe] What makes these factors in particular important?

[Probe] What are some factors that contribute to negative outcomes?

[Probe] What makes these factors in particular important?

From your perspective, who are the other important community partners when it comes to mental health crisis stabilization for children?

[For each agency/organization mentioned] What role do they play?

How would you describe the relationship and communication among the various individuals and groups who work on this issue in your community?

Considering schools, law enforcement, the justice system, and other systems how do you see primary care providers best fitting within the wrap-around care framework?



What do you think are the biggest challenges to community agencies or providers who are treating youth 12 and under with serious mental health problems?

[Probe] How would you like to see those challenges be addressed in your community?

What do you see as the most effective community strategies to address mental health crisis stabilization for young children in your community?

[Probe, if no mention of schools] How do you see schools playing a role?

[Probe, if no mention of health providers] How about mental health providers? Law enforcement and the juvenile justice system?

[Probe, if no mention of families] How do you think families can best be served or supported when they have a child in crisis?

[Probe] Are there any other individuals or organizations that you partner with in the community that have not been mentioned?

[Probe, if answer is broad] Could you give us an example of how these partnerships work to support and stabilize young children experiencing mental health crises?

If you could add or change one thing related to crisis stabilization for youth 12 and under, what would it be?

[If time] Finally, we are developing a questionnaire targeting parents of children 12 and under throughout lowa. Is there anything that you would be interested in knowing from these families that we could add to this questionnaire?



#### **Emergency Department Providers**

In your emergency care service, in the last year or so, how often would you say you or your colleagues treated or assessed children 12 and under who have serious mental health problems?

What are the most common mental health issues that you see in children under 12 in the Emergency Department?

In your experience, have the number of children under 12 with these types of mental health issues been increasing, decreasing, or are they about the same over the last 3-5 years?

[Probe] What thoughts do you have about the factors that may be contributing to the [Increase/Decrease] in mental health disorders in children under 12 years of age?

What, if any, special considerations do you have when treating children under 12?

What staff, if any, do you have in your emergency care service who are specially trained or designated to identify a child who may need help, and refer them to services?

What needs, if any, do you think are not being met by current staff?

In your experience, what are some factors that contribute to positive outcomes when treating children with mental health problems?

[Probe] What makes these factors particularly important?

[Probe] What are some factors that contribute to negative outcomes?

[Probe] What makes these factors particularly important?

Do you have an established or formalized protocol to deal with this type of child?

Would you briefly describe how you provide care for a child in mental health crisis?

[Probe] Does your treatment typically include referral to other providers or agencies?

[Probe, if protocol] What works well with this protocol?

[Probe, if protocol] What, if anything, would you say is missing from this protocol?

[Probe, if no protocol] What arguments would you make for establishing such a protocol?



[Probe, if yes] What would you like to see included in that protocol?

[Probe, if no formalized protocol] Please tell me more about why you would not support a specific protocol?

Please tell me about how prepared you feel your training was for interacting with children and the families of children who have serious mental problems?

[Probe] How about working with their families?

[Probe] Do you feel as though you have enough resources to address these issues?

In your view, what should a primary care physician's main responsibilities be in screening and/or treating children with mental health crises?

Overall, how would you characterize the emergency care service's existing strategies to address the mental health needs of children 12 and under?

Would you say that emergency care services are generally able to send and receive the information they need from families and other agencies or providers to support children under 12 with serious mental health disorders?

When a child has been in crisis and then is discharged, do you know what protocols are in place, if any to assist in the transition?

[Probe] What are the most helpful/valuable dimensions of these transition protocols?

[Probe] What weaknesses exist in the current protocols? What would you design if you had no resource constraints?

[Probe] What would you say is the most critical thing to do following discharge of a youth under 12 to prevent them from being readmitted?

What community resources outside the emergency care services do you rely on when working with a child or family dealing with a mental health crisis?

[Probe] Where do you go first for assistance or referral?

[Probe] Are there agencies that you view as particularly effective? Particularly ineffective?



What do you see as the most effective strategies to address mental health crisis stabilization for young children in your community?

[Probe, if no mention of schools] How do you see schools playing a role?

[Probe, if no mention of health providers] How about mental health providers? Law enforcement and the juvenile justice system? Primary care providers?

[Probe, if no mention of families] How do you think families can best be served or supported when they have a child in crisis?

[Probe] Are there any other individuals or organizations that you partner with in the community that have not been mentioned?

[Probe, if answer is broad] Could you give us an example of how these partnerships work to support and stabilize young children experiencing mental health crises?

What key barriers would you say exist to implementing effective strategies for mental health crisis stabilization in your community?

If you could add or change one thing in your community related to mental health crisis stabilization for children 12 and under, what would that be?

[Probe] How would this most help schools/children/families?

#### Wrap Up

Is there anyone else, either within or outside your practice or setting, who you think would be important for us to speak with to better understand working with this group?

[If time] Finally, we are developing a questionnaire targeting parents of children 12 and under throughout lowa. Is there anything that you would be interested in knowing from these families that we could add to this questionnaire?



#### **Juvenile Justice**

How would you describe your current role in the juvenile justice system?

How long have you been in your current position?

In the course of your work, how often do you encounter children 12 and under with serious mental health problems (or their families)?

In your experience, have the number of children under 12 with these types of mental health issues been increasing, decreasing, or are they about the same over the last 3-5 years?

[Probe] What thoughts do you have about the factors that may be contributing to the [Increase/Decrease] in mental health disorders in children under 12 years of age?

Can you describe an example of a case with which you have been involved that included a serious mental health disorder or crisis with a child 12 or under?

How would you characterize your training for these types of cases with children who have serious mental health problems?

[Probe] How about working with their families? What formal training did you have for this aspect of your work, if any?

We have been talking with several members of your community in numerous different positions, and we have heard many different definitions for what a mental health crisis is. How would you define a serious mental health crisis in a child 12 or under?

Can you describe how cases involving children with mental health issues are treated differently, if at all, compared to other cases?

Could you describe your protocol for dealing with cases that involve a child experiencing a mental health crisis?

[Probe, if protocol] What works well with this protocol?

[Probe, if protocol] What, if anything do you find lacking in this protocol?

[Probe, if no protocol] What arguments would you make for establishing a protocol?

[Probe, if yes] What would you like to see included in such a protocol?



[Probe, if no] Tell me more about why you would not support a specific protocol?

Where does this issue lie in your juvenile court priorities? Is this a significant concern that generates a good deal of discussion or would you say it is a lesser priority?

In your view, what should be the juvenile justice system's responsibility, if any, in assisting this population?

Considering schools, health providers, and the law enforcement, how do you see your institution fitting within the overall system of mental health crisis stabilization for children?

In your experience, what are some factors that contribute to positive outcomes for the children you've seen with serious mental health problems who are in crisis?

[Probe] What makes these factors in particular important?

What are some factors that contribute to negative outcomes?

[Probe] What makes these factors in particular important?

What do you see as the most effective community strategies to address mental health crisis stabilization for young children in your community?

[Probe, if no mention of schools] How do you see schools playing a role?

[Probe, if no mention of health providers] How about mental health providers? Primary care providers?

[Probe, if no mention of families] How do you think families can best be served or supported when they have a child in crisis?

[Probe] Are there any other individuals or organizations that you partner with in the community that have not been mentioned?

[Probe, if answer is broad] Could you give us an example of how these partnerships work to support and stabilize young children experiencing mental health crises?

If there was a single thing you could add or change in your work with kids 12 and under with mental health crises, what would it be?



We will be conducting a broader community survey of families early next year in this and in other nearby counties. What information do you believe would be most valuable from families regarding children's mental health, crisis stabilization and community resource needs?



#### Law Enforcement

What is your current position?

How long have you been in your current position?

In the course of your work, how often do you encounter children 12 and under with serious mental health problems (or their families)?

In your experience, have the number of children under 12 with these types of mental health issues been increasing, decreasing, or are they about the same over the last 3-5 years?

[Probe] What thoughts do you have about the factors that may be contributing to the [Increase/Decrease] in mental health disorders in children under 12 years of age?

How would you characterize your training for these types of cases with children who have serious mental health problems?

[Probe] How about working with their families? What formal training did you have for this aspect of your work, if any?

We have been talking with several members of your community in numerous different positions, and we have heard many different definitions for what a mental health crisis is. How would you define a serious mental health crisis in a child 12 or under?

Could you describe your protocol or approach you take when you are called to a situation and you suspect that a child may be experiencing a serious mental health crisis?

[Probe, if protocol] What works well with this protocol?

[Probe, if protocol] What, if anything do you find lacking in this protocol?

[Probe, if no protocol] What arguments would you make for establishing a protocol?

[Probe, if yes] What would you like to see included in such a protocol?

[Probe, if no] Tell me more about why you would not support a specific protocol?

Where does this issue lie in your law enforcement/juvenile court priorities? Is this a significant concern that generates a good deal of discussion or would you say it is a lesser priority?



In your view, what should be the juvenile justice system's responsibility, if any, in assisting this population?

Considering schools, health providers, and the law enforcement, how do you see your institution fitting within the overall system of mental health crisis stabilization for children?

In your experience, what are some factors that contribute to positive outcomes for the children you've seen with serious mental health problems who are in crisis?

[Probe] What makes these factors in particular important?

What are some factors that contribute to negative outcomes?

[Probe] What makes these factors in particular important?

What do you see as the most effective community strategies to address mental health crisis stabilization for young children in your community?

[Probe, if no mention of schools] How do you see schools playing a role?

[Probe, if no mention of health providers] How about mental health providers? Primary care providers?

[Probe, if no mention of families] How do you think families can best be served or supported when they have a child in crisis?

[Probe] Are there any other individuals or organizations that you partner with in the community that have not been mentioned?

[Probe, if answer is broad] Could you give us an example of how these partnerships work to support and stabilize young children experiencing mental health crises?

If there was a single thing you could add or change in your work with kids 12 and under with mental health crises, what would it be?

[If time] We will be conducting a broader community survey of families early next year in this and in other nearby counties. What information do you believe would be most valuable from families regarding children's mental health, crisis stabilization and community resource needs?



#### Mental Health Care Providers

Our information indicates that you are a: (social worker, psychologist, psychiatrist, behavior specialist, etc). Is that correct?

Tell me a little bit more about your background and how you ended up as a \_\_\_\_\_\_

How long have you been practicing in this community? Overall?

How would you describe your practice type? Is it private solo, private group, agency, school or hospital based?

Thinking about your work with mental health care or services to children under 12, what was your average caseload per month during the past 12 months?

[Probe] What is your overall caseload of children under 12 in the past year?

In your experience, have the number of children under 12 with these types of mental health conditions been increasing, decreasing, or are they about the same over the last 3-5 years?

[Probe] What thoughts do you have about the factors that may be contributing to the increase/decrease in serious mental health disorders in children under 12 years of age?

Would you tell me a little bit more about the type of care or support you provide families and children 12 and under who have serious mental health conditions? That is, children with mental health conditions more serious than typical behavioral disorders such as ADHD.

Please tell me more about any focused training you've had, in any, on the treatment of children under 12 with serious mental health condition?

In treating a child 12 or under with a serious mental health disorder, would you say your approach is more child-centered or family-centered or some combination? And would you please describe any specific treatment frameworks that you prefer?

In your experience, what are some factors that you think contribute most to positive outcomes for the children you've seen with serious mental health conditions who are in crisis?

[Probe] What makes these factors in particular important?

What are some factors that contribute to negative outcomes?

[Probe] What makes these factors in particular important?



What do you see as the most effective community strategies to address mental health crisis stabilization for young children in your community?

[Probe, if no mention of schools] How do you see schools playing a role?

[Probe, if no mention of health providers] How about mental health providers? Primary care providers?

[Probe, if no mention of families] How do you think families can best be served or supported when they have a child in crisis?

[Probe] Are there any other individuals or organizations that you partner with in the community that we have not mentioned?

[Probe, if answer is broad] Could you give us an example of how these partnerships work to support and stabilize young children experiencing mental health crises?

Thinking specifically about mental health crisis stabilization for children 12 and under, in your view, what are the essential community resources or service needs in the North Central lowa community?

[Probe, if focused on Mason City] Thinking more broadly about the both the urban and rural areas of North Central, is there any other essential community resources you would add to that?

[Probe] How do you see integration of services or wraparound approaches – do you view a systems approach as particularly effective or not necessary for good outcomes in children's mental health crisis stabilization?

[Probe] Are there agencies in your community that you view as particularly effective in the work of children's mental health stabilization? Particularly ineffective?

[If preference for wraparound] When you are treating a child in mental health crisis, how much coordination of care do you facilitate and how is that accomplished? Please use an example if that would be easiest.

[Probe] What are the critical/essential aspects of wrap-around care that you think must be in place in order for it to be effective? What groups or agencies should be included in that approach?

[Probe] What barriers or push-back, if any, have you experienced or heard from others when taking the wrap-around approach to care?



What, if any, are some of the barriers you see among families who need your services but aren't reaching YOU (or others) for their child in a mental health crisis?

In your view, how do we better address the needs for mental health crisis stabilization in children under 12?

If you could add or change one thing related to mental health crisis stabilization for children 12 and under in your community, what would that be?

[If time] As part of the needs assessment, we will be conducting a broader community survey of families early next year in this and in other nearby counties. What information do you believe would be most valuable to ask families regarding children's mental health, crisis stabilization and community resource needs?



#### **Primary Care Physicians**

How long have you been a primary care provider?

In your practice, in an average month for how many children under 12 years of age do you provide care?

[Probe] How many of the children that you provide care in the past month have had issues such as behavioral or developmental issues that could be related to a mental health condition?

[Probe] What are the most common mental health issues that you see in children under 12 years of age?

About how often do you encounter children 12 and under with serious mental health problems or mental health crises?

In your experience, have the number of children under 12 with these types of mental health issues been increasing, decreasing, or are they about the same over the last 3-5 years?

[Probe] What thoughts do you have about the factors that may be contributing to the [INCREASE/DECREASE] in mental health disorders in children under 12 years of age?

In your experience, what are some factors that contribute to positive outcomes when treating children with mental health problems?

[Probe] What makes these factors in particular important?

[Probe] What are some factors that contribute to negative outcomes?

[Probe] What makes these factors in particular important?

Do you have an established or formalized protocol to deal with this type of child?

Would you briefly describe how you provide care for a child in mental health crisis?

[Probe] Does your treatment typically include referral to other providers or agencies?

[Probe, if protocol] What works well with this protocol?

[Probe, if protocol] What, if anything, would you say is missing from this protocol?

[Probe, if protocol] What arguments would you make for establishing such a protocol?



[Probe, if yes] What would you like to see included in that protocol?

[Probe, if no formalized protocol] Please tell me more about why you would not support a specific protocol?

Please tell me about how prepared you feel your training was for interacting with children and the families of children who have serious mental problems?

[Probe] How about working with their families?

[Probe] Do you feel as though you have enough resources to address these issues?

In your view, what should a primary care physician's main responsibilities be in screening and/or treating children with mental health crises?

Considering schools, law enforcement, the justice system, and other systems how do you see primary care providers best fitting within the wrap-around care framework?

What do you think are the biggest challenges to primary care physicians who are treating youth 12 and under with serious mental health problems?

[Probe] How would you like to see those challenges be addressed in your community?

What do you see as the most effective community strategies to address mental health crisis stabilization for young children in your community?

[Probe, if no mention of schools] How do you see schools playing a role?

[Probe, if no mention of health providers] How about mental health providers? Law enforcement and the juvenile justice system?

[Probe, if no mention of families] How do you think families can best be served or supported when they have a child in crisis?

[Probe] Are there any other individuals or organizations that you partner with in the community that have not been mentioned?

[Probe, if answer is broad] Could you give us an example of how these partnerships work to support and stabilize young children experiencing mental health crises?



If there was a single thing you could add or change in your work with kids 12 and under with mental health crises, what would it be?

Is there anyone else, either within or outside your practice or setting, who you think would be important for us to speak with to better understand working with this group?

[If time] Finally, we are developing a questionnaire targeting parents of children 12 and under throughout lowa. Is there anything that you would be interested in knowing from these families that we could add to this questionnaire?



#### **School Administrators & Educators**

Experience with Children's Mental Health Crises
What is your position and how long have you been in this role?

In your district/school, in the last year or so, how often would you say you or your educators interact with children 12 and under who have serious mental health problems? That is, children with mental health issues more serious than behavioral disorders such as ADHD.

What behaviors or symptoms have been observed or reported in these children that suggest they have more serious mental health issues?

How would you define a mental health crisis in a child 12 or under?

In your experience, have the number of children under 12 with these types of mental health issues been increasing, decreasing, or are they about the same over the last 3-5 years?

[Probe] What thoughts do you have about the factors that may be contributing to mental health disorders in children under 12 years of age?

Where does this issue lie in your school/district priorities? Is this a significant concern that generates a good deal of discussion or would you say it is a lesser priority?

What staff, if any, in your school/district are specially trained or designated to identify or treat a child who may need help, and/or refer them to services?

[Probe] What needs, if any, do you think are not being met by current staff?

[If none] How would you describe elementary and/or middle school teachers' skills and comfort in addressing mental health crises among young students?

In your view, what should be the school's responsibilities, if any, in assisting these students and families?

Overall, how would you characterize the district's/school's existing strategies to address the mental health needs of children 12 and under?

If/when you have a student experiencing mental health issues, what protocol is in place for assistance and/or referral?

[Probe, if no specific protocol] Is there any informal strategy in place you could share that addresses crisis stabilization for young children with mental health issues?



[Probe] What strategies would you say work particularly well?

[Probe] What are the areas that you think could be improved?

Overall, how would you characterize the preparation of teachers and other school professionals to deal with a young child who is experiencing a mental health crisis?

What community resources outside the district/school/AEA do you rely on when working with a child or family dealing with a mental health crisis?

[Probe] Where do you go first for assistance or referral?

[Probe] Are there agencies or providers that you view as particularly effective? Particularly ineffective?

What key barriers would you say exist to implementing effective strategies for effective mental health crisis stabilization in your community?

Considering schools, health providers, and the law enforcement, how do you see your institution fitting within the overall system of mental health crisis stabilization for children?

In your experience, what are some factors that contribute to positive outcomes for children with serious mental health problems?

[Probe] What makes these factors in particular important?

What are some factors that contribute to negative outcomes?

[Probe] What makes these factors in particular important?

When a child has been in crisis and then returns to the classroom, what protocols are in place, if any to assist in the transition?

[Probe] What are the most helpful/valuable dimensions of these transition protocols?

[Probe] What weaknesses exist in the current protocols? What would you design if you had no resource constraints?

[Probe, if not mentioned] What have you heard about therapeutic classrooms or therapeutic schools?



[Probe] What aspects of this approach do you believe would work well in your community? Not work?

How would you characterize the communication flow related to students dealing with mental health crises?

[Probe] Would you say that schools are generally able to send and receive the information they need from families and other agencies or providers to support young students with serious mental health disorders?

If you could add or change one thing in your community related to mental health crisis stabilization for children 12 and under, what would that be?

[Probe] How would this most help schools/children/families?

Wrap Up (25:00)

Is there anyone else in the community with special experience or expertise in children's mental health crisis stabilization who you believe would be especially important for us to interview?

[If time]: We will be conducting a broader community survey of families early next year in this and in other nearby counties. What information do you believe would be most valuable from families regarding children's mental health, crisis stabilization and community resource needs?



# **Focus Group Moderator Guides**

## **Parent Focus Group**

[INTRODUCTIONS & GENERAL OVERVIEW OF PROCESS]

## **General Concerns about Raising Children**

I would like to begin our discussion with some general questions about raising children – focusing on those under 12.

Overall, what would you say is most challenging about raising young children today? What is toughest? Easiest/most enjoyable?

What is the most challenging aspects of addressing kids' health needs (health insurance, finding a provider, cost of care, getting sick, safety issues - getting hurt)?

[Probe by one or more topics, if time allows]

Development (are they growing OK? Issues with eating, temper tantrums, sleep)? Who will take care of them (childcare arrangements, availability, cost, quality)? Family relationships (sibling rivalry, stress on family unit, current and future financial concerns)? Adequacy as a parent?

What concerns you the most? Why?

Who or where do you turn to for help with things that worry you?

### Children's Well-being

Focusing in more detail on some topics related to health and wellness in your children, when you think about your child's health, what do you think about?

Probe: How would you define good physical health? Good mental health?

### **Knowledge/Information**

In general, how knowledgeable do you feel about your understanding of physical health in children as children grow?

How knowledgeable do you feel about your understanding of mental health in children as children grow?

Where do you go to get information about your parenting questions or concerns about physical health?



Who or where do you seek information about mental health? [Probe] Are there any specific people, organizations or agencies you would seek out or recommend to others if you or they needed information on children's mental health?

How would you characterize the information available about mental health? Is it useful? Complete? Easy to understand?

[Probe] What made it useful? What would you like to see to improve children's mental health information available to parents?

#### Crisis identification and intervention

All kids have times of struggle or rough patches. Other situations seem more serious. What circumstances or behaviors would you characterize as a "crisis" in a young child? What would that look like?

How many of you have experienced something with a young child that you would consider a crisis?

When that crisis situation occurred with your child or children, what did you do? To whom did you reach out for information, support or assistance?

What happened after you sought assistance? Were you satisfied with the help available? How did it help or not help?

Thinking about your own or others' needs during a child's mental health crisis, what do you see as the biggest barriers to getting help or quality treatment for the child? [PROBE ONLY IF NOT MENTIONED] Health insurance coverage?

### Health-care access, use and barriers

Do you or did you have a regular doctor or other healthcare provider for your young child?

[If yes] Thinking back to those visits, what topics do you recall being discussed at the visits?

[Probe] Child development (age you can expect your child to accomplish a particular task) Child rearing (eating, sleeping, play, temper tantrums)

Family concerns (stress on parent, sibling rivalry)

Did the doctor suggest and/or refer you to other resources or services in the community?

What kinds of things would you like to discuss with your child's health care provider?



Did you or do you talk to these healthcare providers about any mental health or behavior concerns you have for your children?

[If yes] Were you satisfied with the care your child received from their regular doctor for these mental health concerns? IF NOT? What were you not satisfied with?

How accessible would you say mental health support is at the schools? In the broader community? [Probe] Specifically regarding access to services, what are the main barriers to children's use of services?

What aspects of care and the services you have received worked best/ did you consider most useful? Why?

What aspects were not as good, and could be improved? Why?

[Time permitting] Aside from the aspects that worked better or worse, was there something in the process that was not what you expected?

[Probe] appointments? waiting lists? Pre-approval for care? Forms or screenings? Sharing of information from one agency to the next?

Thinking over the entire process, what steps or communication should there be as a child moves through referral and treatment and transitions back to family and school?

Probes: What needs to happen? What are the gaps now and why are these gaps important?

If you were designing mental health services for children in your community, what would that look like? From your perspective, what should this be? How would it be different from what you have experienced?

What services not currently available in your community would you like to have?

[Probe] Where do you see these services being provided? School setting? The doctor or paediatrician clinic? Community?

#### Stigma

What are the biggest fears or worries you or other parents have when a child has a mental health condition?

Sometimes parents are concerned about what others might think or say if they talk about their kids' emotional challenges or mental health conditions. How much would you say this is an issue or concern for families you know? Are these concerns based on real experiences or broader concerns about stigma or stereotypes about people's views of mental health conditions from earlier times? Extended family? Community?



If you have experienced having a child with a mental health crisis, how much information did you provide to the school? Did others provide information to the school or your child's teacher?

What would you tell other families about children's mental health challenges and sharing information about those with others including school personnel or professional treatment resources?

# Wrap Up

If you could say one thing that you would have liked to have known or think is critical to know when your child began/begins to have mental health problems, what would it be?

What else is important that we haven't touched on?



## Youth Focus Group - Alternative School

[INTRODUCTIONS AND GENERAL OVERVIEW OF PROCESS]

#### General

I would like to begin our discussion with some general questions about teen issues.

What do you consider to be the most important issues facing teens in your community?

[Listen for: health issues relative to other topics, e.g. substance abuse, teen pregnancy, family problems, career/education choices]

### **Definitions/Knowledge**

Brainstorm all the words and images evoked by the term "mental health"

Where do you go or who do you talk to when you need information about mental health concerns?

Who or what source do you trust most for this kind of info? Why?

## Community, schools, & stigma

How do mental health issues affect you and your friends? How does another student's mental health issues affect you and your friends?

If you are struggling or have a friend who is struggling, what is most helpful for getting back to a good place?

How does it go when you talk about emotional and mental health issues with parents? Teachers? Friends? [Probe] Is talking about mental health stuff the same or different than other topics? What is difficult when talking about mental health issues?

What do you think kids are concerned about when it comes to telling others about what is going on in their life in terms of emotional or mental health topics?

### Health-care access, use and barriers

What words do you or your friends use someone is starting to feel like they need help feeling better? [Listen for the words they use to describe the event: freaking out, losing it, ...]

What are the warning signs?

Now I would like to talk specifically about how to get help. What would you say are the resources in your community to support teen mental health?



If you or someone close to you has gotten help or treatment, what aspects of getting care and the services needed worked best? What didn't work well?

Think about if you are in charge. What would the ideal system or process be if you could build it? What would be particularly helpful or make things worse from your perspective?

# Wrap up

If you could say one thing that you would have liked others to know about teens and children going through a hard time, what would it be?



## **Youth Focus Group - YSS**

[INTRODUCTIONS AND OVERVIEW OF PROCESS]

## **Participant introductions**

Please share your first name, age, and favorite pastime.

#### General

I would like to begin our discussion with some general questions.

What would you say are the most important or difficult issues facing teens in your community?

[Listen for: health issues relative to other topics, e.g. substance abuse, teen pregnancy, family problems, career/education choices]

### Definition, Knowledge, & Information about physical vs mental health

Brainstorm all the words and images evoked by the term "mental health"

Who do you talk to or where do you look for info when you have a concern about your own emotional health? A friend or siblings' mental health?

Who or what do you trust most for this kind of info? Why?

## Community, schools, & stigma

How do mental health issues affect you and your friends? How does another student's mental health issues affect you and your friends?

If you have been struggling the most, what do you find most helpful in recovery for getting back to a good place?

What do you wish would have been done for you or for your family during the process of getting you to a more stable place?

How does it go when you talk about emotional and mental health issues with parents? Teachers? Friends? [Probe] What is difficult when talking about mental health issues?

What are some of your fears or what do you think others' are concerned about when it comes to telling others about what is going on in their emotional life?



### Health-care access, use and barriers

What makes you feel more or less comfortable asking for help when you are having a hard time?

Now I would like to talk specifically about how to get help. What resources in your community would you say support or treat teen mental health conditions?

After having gotten help or treatment, what aspects of getting care and the services needed worked best? What didn't work well?

What would you like people to know about teens who go through what you are going through?

Think about if you are in charge. What would the ideal system or process be if you could build it? What would be particularly helpful or make things worse from your perspective?

## Wrap up

If you could say one thing that you would have liked others to know about teens and children going through a hard time, what would it be?



# **Appendix B: Phase 2 Methods**

# **Study Design**

During the second part of a multiphase mixed design telephone interviews of parents and guardians and focus group of parents of children under 12 years old were conducted to better understand awareness of and experiences with children' mental health and services in north central lowa (Figure 19). The telephone interviews were conducted first followed by the focus group of parents. The focus group was added to the data collection activities once the telephone lists were exhausted and the number of respondents had not reached the original goal of 400 participants. The design and analysis strategy follows an explanatory sequential mixed methods design in that the quantitative results from the telephone survey were used to inform the types of questions asked to the participants in the focus group. In reporting the results, the quantitative results are first described followed by how the qualitative results inform the quantitative findings. The goal is for the qualitative data to provide more nuance and depth than would be possible to obtain from the quantitative results alone (Creswell, 2014, p. 225).

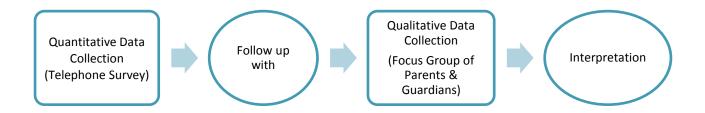


Figure 18. Explanatory Sequential Mixed Method Design

## Limitations

It is important to note that the findings are based on a telephone survey using a non-probability sample. A targeted list was used to increase data collection efficiencies with the tradeoff that the list does not represent all of the parents and guardians in the geographic area, only those who have been added to the targeted list. In order to generalize findings to the geographic area, a probability-based sampling strategy would be required and population parameters needed to allow for weighting adjustments to be made. Thus, the results of the telephone survey should not be used to generalize to the seven county area. Rather, the information represents the attitudes, perceptions, and experiences of parents and guardians of a targeted sample of households from the seven county area.

The focus group, by design, is a qualitative type of data collection that does not produce generalizable results. There may be implied measurement properties of qualitative data when descriptions such as "most", "several", or "a few" are used. However, this is not an appropriate interpretation of qualitative findings. The authors aimed to be mindful when using these descriptive qualifiers, so as not to imply a quantitative assumption about the findings. In all cases, descriptions such as "most" or "a few" simply mean the view or perspective was not unanimous (i.e. it was neither held by "none" nor "all"). Caution should be used to avoid inferring a quantitative inference from statements that use these descriptions.



# **Telephone Interviews**

## **Description of the sample**

The characteristics of the respondents from the telephone survey are indicated in Table 7. Respondents were 258 mothers, fathers, and guardians of children under 12 years old, residing in North Central Iowa. Their age ranged from 25 to 62, with an average of 41 years. Most of them were non-Hispanic whites. Regarding educational attainment, 44% of the sample graduated from college. As for annual household income, approximately one fifth reported earning less than \$50,000; 39% earned between \$50,000 and \$100,000, and approximately 40% reported earning more than \$100,000. Almost 20% of the sample reported having children under 3, and 97% reported having children 3 to 12 years old. The sample of parents for the telephone survey was a targeted list of parents and the data were not weighted to derive point estimates.

Table 7. Sample

	% (n)
Total Sample Size	258
Average age (SD)	41years old (7)
Sex	
Male	30 (78)
Female	70 (180)
Race	
White	97(250)
Non-White	3 (8)
Hispanic, Latino, or Spanish origin	2 (5)
Education	
High school, GED or less	24 (63)
Some college/technical school	31 (81)
College graduate and more	44 (114)
Annual income	
Less than \$50,000	20 (71)
\$50,000 to \$100,000	39 (92)
More than \$100,000	31 (73)
Children in the household	
Children under 3	18 (46)
3 to 12	97 (251)
13-19	50 (128)
County	
Cerro Gordo	25 (44)
Chickasaw	15 (26)
Floyd	16 (28)
Hancock	7 (13)
Mitchell	17 (30)
Winnebago	13.6 (24)
Worth	6.8 (12)

characteristics



## Questionnaire

As the telephone survey was the second phase of the needs assessment, the questionnaire was informed by the results of the in-depth interviews conducted during phase one. The main topics covered in the survey are summarized in Table 8, and the questionnaire is available within Appendix B.

Table 8. Main topics covered in the interviews and focus group

## **Key topics covered**

Challenges raising children today
Incidence of mental health conditions in children
Perceptions of children's physical and mental health
Perceptions and experiences with mental health crises
Attitudes towards mental health
Barriers to mental health treatment
Experiences with mental health services



#### **Data collection**

Interviews were completed between March 3, and April 9, 2017, and averaged 23 minutes in length. Both English and Spanish interviewing was available but all interviews were conducted in English. Interviews were conducted by trained interviewers at the Center for Social & Behavioral Research at the University of Northern Iowa. No incentives were offered for participation.

Targeted sample frames were used for both landline and cell phone frames in the study. Samples were obtained from Marketing Systems Group (MSG) and come from consumer databases of phone numbers. The targeted sample databases come from sources such as public records, phone directories, U.S. Census data, consumer surveys, and other MSG proprietary sources which are used to append a phone number to a record. Respondents were screened for eligibility and were deemed eligible if they were parents or legal guardians of a child twelve years of age or younger and lived in one of the seven counties of interest. The adult most knowledgeable about the child/children in the household was requested as the selected respondent.

A total of 258 interviews were completed. This included 81 interviews from the cellular RDD sample and 177 interviews from the landline RDD sample.

The American Association for Public Opinion Research (2016), response rate (RR3) and cooperation rate (COOP3) for the survey were 16%, and 50%, respectively.



## **Telephone Questionnaire**

#### Intro1

HELLO, my name is [YOUR NAME] and I am calling from the Center for Social and Behavioral Research at the University of Northern Iowa. Researchers here are conducting a study to find out about the health and emotional well-being of children in your community and experiences with healthcare resources and services in your area.

#### **Phone**

Is this XXX-XXX-XXXX?

- 1. Correct Number
- 2. Number is not the same

[Thank you very much, but I seem to have dialed the wrong number. It's possible that your number may be called at a later time.]

## 7. DON'T KNOW/NOT SURE

### Cell

Is this a cell phone?

1. YES Cell, personal

3. YES Cell, business

2. NO, landline

[SKIP TO SAFE]

[Thank you very much, but we are only interviewing lowa households at this time.]

### **Home Phone**

Is this your home phone in Iowa?

- 1. Yes
- 2. No, not in Iowa
- 3. No, is a business
- 7. DON'T KNOW/NOT SURE
- 9. REFUSED

[IF 2, 3, 7 or 9, Thank you very much, but we are only interviewing lowa households at this time.] County



In what county are you currently living?

- 1. Cerro Gordo
- 2. Chickasaw
- 3. Floyd
- 4. Hancock
- 5. Mitchell
- 6. Winnebago
- 7. Worth
- 8. COUNTY NOT ELIGIBLE

[Thank you very much, but we are only interviewing adults in certain parts of lowa for this study, and your county is not on my list.]

### Children

Since this study is about the health and well-being of children, can you tell me if you have any children 12 years of age or younger in your household?

- 1. Yes
- 2. No
- 7. DON'T KNOW/NOT SURE
- 9. REFUSED

[IF 2, 7 or 9 EXIT: Our study is for households with children 12 years of age or younger. Thank you for your time.]

#### **Adult**

Are you the adult, age 18 or older, in the household who knows the most about the health and well-being of the children living in your home?

Yes and respondent is male
 Yes and respondent is female
 SKIP TO CONFIDENTIALITY 1
 SKIP TO CONFIDENTIALITY 1

3. No

- 7. DON'T KNOW/NOT SURE
- 9. REFUSED

### Speak

May I speak with the adult who is most knowledgeable about the health of the children in the home?

1. Yes, coming to the phone [SKIP TO INTRO2]

2. No, not available



#### **New Contact**

When would be a good time to reach that person at this number and may I have their first name?

1. Callback time/name

[ENTER NAME IN MESSAGE] [SKIP TO INTRO2]

2. Available at another number

#### **New Number**

Could I leave a phone number or email address that they could reach us at to set up a callback time?

[INTERVIEWER NOTE: IF PERSON ON PHONE GIVES YOU A NEW NUMBER FOR THE MOST KNOWLEDGEABLE ADULT, WRITE DOWN THE NUMBER AND INCLUDE IT IN YOUR MESSAGE. USE THE FOLLOWING SCRIPT: "IN ORDER FOR US TO BE ABLE TO CONTACT THAT NUMBER, WE NEED THEM TO CALL OR EMAIL US WITH PERMISSION TO CONTACT THEM."]

- 1. Gave phone number/email address
- 2. Would not take information to contact CSBR [AUTO CODE 2111]

#### Intro2

HELLO, my name is [YOUR NAME] and I am calling from the Center for Social and Behavioral Research at the University of Northern Iowa. Researchers here are conducting a study to find out about the health and emotional well-being of children in your community and experiences with healthcare resources and services in your area.

### Confidentiality1

Let me tell you more about the study before we go on. Your phone number has been chosen randomly, and I would like to ask some questions about your experiences, knowledge, and perceptions of children's health and emotional well-being. We are interested in your views regardless of how much you might know about this topic or how much familiarity you might have with healthcare resources in your area.

For most people the interview takes about 20 minutes. Participation is voluntary and your responses are confidential. No identifying information will be stored with your responses. The results of this interview will not be reported individually. There are no costs, payments, or direct benefits to you for participating in the interview; however, your participation in the study is very important to us as your answers will be combined with many others to help us understand views on healthcare of children. Risks are minimal and similar to those typically encountered in your day-to-day life. You do not have to answer any question you do not want to, and you can end the interview at any time. I can provide the name and telephone number of the project manager or the administrator in the Office of Research at UNI if you have any questions about the study.



### Safe

Is this a safe time to talk with you? If you are now driving a car or doing any activity that requires your full attention, I will call you back at a later time.

Yes
 No

[SKIP TO CELL ADULT]

[SET APPOINTMENT IF POSSIBLE.]

When would be a better time to reach you?

### **Cell Adult**

Are you an adult 18 years of age or older?

- 1. Yes
- 2. No
- 7. DON'T KNOW/NOT SURE
- 9. REFUSED

[IF 2, 7 or 9, Thank you very much, but we are only interviewing persons aged 18 or older at this time.]

## County

In what county are you currently living?

- 1. Cerro Gordo
- 2. Chickasaw
- 3. Floyd
- 4. Hancock
- 5. Mitchell
- 6. Winnebago
- 7. Worth
- 8. County not eligible

[Thank you very much, but we are only interviewing adults in certain parts of Iowa for this study, and your county is not on my list.]



### Children

Since this study is about the health and well-being of children, can you tell me if you have any children 12 years of age or younger in your household?

- 1. Yes
- 2. No
- 7. DON'T KNOW/NOT SURE
- 9. REFUSED

[IF 2, 7 or 9 EXIT: Our study is for households with children 12 years of age or younger. Thank you for your time.]

### CellAdult2

Are you the adult in your household who knows the most about the health and well-being of the children living in your home?

Yes and respondent is male
 Yes and respondent is female
 SKIP TO CONFIDENTIALITY 2
 SKIP TO CONFIDENTIALITY 2

3. No

- 7. DON'T KNOW/NOT SURE
- 9. REFUSED

## Speak

May I speak with the adult who is most knowledgeable about the health of the children in the home?

1. Yes, coming to the phone [SKIP TO INTRO2]

2. No, not available

## **New Contact**

When would be a good time to reach that person at this number and may I have their first name?

1. Callback time/name [ENTER NAME IN MESSAGE] [SKIP TO INTRO2]

2. Available at another number



#### **New Number**

Could I leave a phone number or email address that they could reach us at to set up a call time?

[INTERVIEWER NOTE: IF PERSON ON PHONE GIVES YOU A NEW NUMBER FOR THE MOST KNOWLEDGEABLE ADULT, WRITE DOWN THE NUMBER AND INCLUDE IT IN YOUR MESSAGE. USE THE FOLLOWING SCRIPT: "IN ORDER FOR US TO BE ABLE TO CONTACT THAT NUMBER, WE NEED THEM TO CALL OR EMAIL US WITH PERMISSION TO CONTACT THEM."]

- 1. Gave phone number/email address
- 2. Would not take information to contact CSBR [AUTO CODE 2111]

#### Intro2

HELLO, my name is [YOUR NAME] and I am calling from the Center for Social and Behavioral Research at the University of Northern Iowa. Researchers here are conducting a study to find out about the health and emotional well-being of children in your community and experiences with healthcare resources and services in your area.

## Confidentiality2

Let me tell you more about the study before we go on. Your phone number has been chosen randomly, and I would like to ask some questions about your experiences, knowledge, and perceptions of children's health and emotional well-being. We are interested in your views regardless of how much you might know about this topic or how much familiarity you might have with healthcare resources in your area.

For most people the interview takes about 20 minutes. Participation is voluntary and your responses are confidential. No identifying information will be stored with your responses. The results of this interview will not be reported individually. There are no costs, payments, or direct benefits to you for participating in the interview; however, your participation in the study is very important to us as your answers will be combined with many others to help us understand views on healthcare of children. Risks are minimal and similar to those typically encountered in your day-to-day life. You do not have to answer any question you do not want to, and you can end the interview at any time. I can provide the name and telephone number of the project manager or the administrator in the Office of Research at UNI if you have any questions about the study.

### Section 1. General concerns about children's well-being

QG1. What, in your opinion, is the biggest challenge raising young children today?

[OPEN ENDED]



QG2. When you think of physical well-being or physical health in young children, what comes to mind?

## [OPEN ENDED]

- QG3. How knowledgeable are you about issues related to physical health in young children as they grow? Would you say you are...
  - 1. Not at all knowledgeable,
  - 2. Slightly knowledgeable,
  - 3. Somewhat knowledgeable, or
  - 4. Very knowledgeable?
  - 7. DON'T KNOW/NOT SURE
  - 9. REFUSED
- QG4. With regard to the resources available for physical health for young children in your community, would you say the resources available are...
  - 1. Less than needed,
  - 2. About right, or
  - 3. More than needed?
  - 7. DON'T KNOW/NOT SURE
  - 9. REFUSED
- QG5. Does your child have a regular doctor or healthcare provider?
  - 1. Yes
  - 2. No
  - 7. DON'T KNOW/NOT SURE
  - 9. REFUSED
- QG6. When you think about mental health in young children, what comes to mind?

# [OPEN ENDED]

QG7. Thinking about mental health in young children, what is the age of the youngest child you've known, or heard of, with a serious mental health condition?



## 88. DON'T KNOW OF A CHILD WITH SERIOUS CONDITION

## 77. DON'T KNOW/NOT SURE

## 99. REFUSED

- QG8. How knowledgeable are you, about issues related to mental health, in young children as they grow? Would you say you are...
  - 1. Not at all knowledgeable,
  - 2. Slightly knowledgeable,
  - 3. Somewhat knowledgeable, or
  - 4. Very knowledgeable?

## 7. DON'T KNOW/NOT SURE

- 9. REFUSED
- QG9. With regard to the resources available for mental health for young children in your community, would you say the resources available are...
  - 1. Less than needed,
  - 2. About right, or
  - 3. More than needed?

## 7. DON'T KNOW/NOT SURE

- 9. REFUSED
- QG10. How familiar are you with the services in your community for young children with mental health conditions? Would you say you are...
  - 1. Not at all familiar,
  - 2. Somewhat familiar, or
  - 3. Very familiar?
  - 7. DON'T KNOW/NOT SURE
  - 9. REFUSED



QG11. If you were to have questions or concerns about your child's mental health, where would you go for answers?

# [SELECT UP TO THREE – DO NOT READ]

- 11. Doctor, pediatrician, or primary care provider
- 12. Mental healthcare provider
- 13. School official (e.g., counselor, principal, teacher)
- 14. Family, friends
- 15. Social media
- 16. Internet and websites
- 17. Other [SPECIFY]
- 77. DON'T KNOW/NOT SURE
- 99. REFUSED
- QG12. Have you ever been in contact with or visited an agency, counselor or other healthcare provider regarding a mental health condition in your child or children?
  - 1. Yes

2. No [SKIP TO QG20]

7. DON'T KNOW/NOT SURE [SKIP TO QG20]
9. REFUSED [SKIP TO QG20]

QG13. What agency, counselor or other type of healthcare provider did you contact or visit?

## [OPEN ENDED]

QG14a. Have any of your children been diagnosed with a mental health condition?

1. Yes

2. No [SKIP TO QG16]

7. DON'T KNOW/NOT SURE [SKIP TO QG16]
9. REFUSED [SKIP TO QG16]



QG14b. Have they received treatment?

1. Yes

2. No [SKIP TO QG16]

7. DON'T KNOW/NOT SURE [SKIP TO QG16]
9. REFUSED [SKIP TO QG16]

- QG15. What type of treatment did they receive? Was it...
  - 1. Outpatient treatment,
  - 2. Inpatient treatment,
  - 3. Residential treatment,
  - 4. Outpatient and Residential treatment, or
  - 5. Some other type of treatment [SPECIFY]?
  - 7. DON'T KNOW/NOT SURE
  - 9. REFUSED
- QG16. Overall, how satisfied were you with the services and treatment that your child received? Would you say you were...
  - 1. Very dissatisfied,
  - 2. Dissatisfied,
  - 3. Satisfied, or
  - 4. Very satisfied?
  - 8. NEITHER SATISFIED NOR DISSATISFIED
  - 7. DON'T KNOW/NOT SURE
  - 9. REFUSED
- QG17. In your opinion, what worked well?

[OPEN ENDED]

QG18. In your opinion, what did not work well?

[OPEN ENDED]



\_\_\_ [NUMBER OF TIMES]

Y	A YSS ORGANIZATION				
QG19.	If you could make one suggestion to improve the process you went through to make sure your child received the necessary mental health care services or treatments, what would it be?				
	[OPEN ENDED]				
[SKIP T	[SKIP TO QG23]				
QG20.	What resources or providers would you contact if your child had a mental health condition?				
	[OPEN ENDED]				
QG21.	If one of your children showed symptoms of a possible mental condition, how easy or difficult would it be for you to find professional help? Would you say				
	<ol> <li>Very easy,</li> <li>Somewhat easy,</li> <li>Somewhat difficult, or</li> <li>Very difficult?</li> </ol>	[SKIP TO QG23] [SKIP TO QG23]			
	7. DON'T KNOW 9. REFUSED	[SKIP TO QG23] [SKIP TO QG23]			
QG22.	. What makes it difficult to find professional help?				
	[OPEN ENDED]				
QG23.	Regardless of your personal experience, what circumstances or behaviors would you characterize as a "mental health crisis" in a child?				
	[OPEN ENDED]				
QG24.	Have any of your children ever experienced	what you would consider a "mental health crisis"?			
	1. Yes 2. No 7. DON'T KNOW/NOT SURE 9. REFUSED	[SKIP TO QG30] [SKIP TO QG30] [SKIP TO QG30]			
QG25.	Approximately how many times has this occurred?				



76. 76 or more times

77. DON'T KNOW/NOT SURE

99. REFUSED

QG26. What was the child's age when the first crisis occurred?

\_\_\_\_ [CHILD'S AGE]

77. DON'T KNOW/NOT SURE

99. REFUSED

QG27. What did you do to help stabilize your child's situation during the first crisis?

**IF NEEDED, SAY**: What kind of help did you seek, if any?

[OPEN ENDED]

QG27a. Did you call or go anywhere else?

## [DO NOT READ - SELECT ALL THAT APPLY]

- 11. Hospital emergency department
- 12. Urgent care clinic
- 13. Primary care provider
- 14. Psychiatrist/psychologist/therapist office
- 15. Social service agency or department (DHS)
- 16. Drug or alcohol outpatient clinic
- 17. Church or other religious building
- 18. School officials (principal, counselor, nurse)
- 19. Friends, family members
- 20. Social media
- 21. Website [SPECIFY WHAT WEBSITE]
- 22. Other [SPECIFY]
- 88. NOTHING ELSE
- 77. DON'T KNOW/NOT SURE
- 99. REFUSED

[IF QG25 = 1, SKIP TO QG29]

QG28. What did you do to help stabilize your child's situation during the most recent crisis?

**IF NEEDED, SAY**: What kind of help did you seek, if any?



## [OPEN ENDED]

QG28a. Did you call or go anywhere else?

## [DO NOT READ - SELECT ALL THAT APPLY]

- 11. Hospital emergency department
- 12. Urgent care clinic
- 13. Primary care provider
- 14. Psychiatrist/psychologist/therapist office
- 15. Social service agency or department (DHS)
- 16. Drug or alcohol outpatient clinic
- 17. Church or other religious building
- 18. School officials (principal, counselor, nurse)
- 19. Friends, family members
- 20. Social media
- 21. Website [SPECIFY WHAT WEBSITE]
- 22. Other [SPECIFY]
- 88. NOTHING ELSE
- 77. DON'T KNOW/NOT SURE
- 99. REFUSED

## [SKIP TO QG32]

Q29 Was reworded and changed to QG27a and QG28a on 2/21/17. Programming now skips Q29.

QG30. If your child were to experience a mental health crisis, what do you think you would do to help stabilize the child's situation?

**IF NEEDED, SAY**: What kind of help would you seek, if any?

[OPEN ENDED]

QG30a. Would you call or go anywhere else?

## [DO NOT READ - SELECT ALL THAT APPLY]

11. Hospital emergency department



- 12. Urgent care clinic
- 13. Primary care provider
- 14. Psychiatrist/psychologist/therapist office
- 15. Social service agency or department (DHS)
- 16. Drug or alcohol outpatient clinic
- 17. Church or other religious building
- 18. School officials (principal, counselor, nurse)
- 19. Friends, family members
- 20. Social media
- 21. Website [SPECIFY WHAT WEBSITE]
- 22. Other [SPECIFY]
- 88. NOTHING ELSE
- 77. DON'T KNOW/NOT SURE
- 99. REFUSED

## Q31 Was reworded and changed to QG30a on 2/21/17. Programming now skips Q31.

- QG32. Thinking about the last five years, would you say that the number of children age 12 or younger, with mental health conditions, in your community has been increasing, decreasing, or is about the same?
  - 1. Increasing
  - 2. About the same
  - 3. Decreasing
  - 8. HAVEN'T LIVED HERE FOR 5 YEARS
  - 7. DON'T KNOW/NOT SURE
  - 9. REFUSED
- QG33. Have you ever heard of nurtured heart approach or nurtured heart training?
  - 1. Yes

2. No [SKIP TO QG35]

7. DON'T KNOW/NOT SURE [SKIP TO QG35]
9. REFUSED [SKIP TO QG35]

QG34. What is your understanding of the nurtured heart approach?

[OPEN ENDED]



QG35. In what ways do you think schools should assist children with mental health conditions, if at all?

## [OPEN ENDED]

## Section 2. Stigma

QS1. What are the biggest fears or worries you think parents have when their child has a mental health condition?

[OPEN ENDED]

QS2. Sometimes parents are concerned about what others may think or say when talking about children's mental health. Of the parents you know, how concerned are they about this particular issue?

Would you say...

- 1. Not at all concerned,
- 2. Slightly concerned,
- 3. Somewhat concerned, or
- 4. Very concerned?
- 7. DON'T KNOW/NOT SURE
- 9. REFUSED

QS3. I'm going to read some statements about attitudes toward children with mental health issues.

Please tell me whether you strongly agree, agree, disagree, or strongly disagree with each of the following statements.

[RANDOMIZE LIST]



- a. Most people look down on children who visit a counselor because they have emotional or behavioral problems.
- b. Most people believe that children with emotional or behavioral problems will get better someday.
- c. Most children would be happy to hang out with someone who has emotional or behavioral problems.

## Do you...

- 1. Strongly agree,
- 2. Agree,
- 3. Disagree, or
- 4. Strongly disagree?
- 8. NEITHER AGREE NOR DISAGREE
- 7. DON'T KNOW/NOT SURE
- 9. REFUSED

#### Section 3. Barriers to treatment

QB1. What do you think are some possible barriers that would prevent you from seeking treatment for your child if diagnosed with a mental health condition?

## [DO NOT READ – SELECT ALL THAT APPLY]

- 11. Lack of services or providers in the area
- 12. Not being able to get an appointment soon enough
- 13. Having to travel too far to obtain assistance
- 14. No evening or weekend hours
- 15. Services are too expensive
- 16. No insurance to pay for the services needed
- 17. Do not have transportation
- 18. Something else [SPECIFY]
- **88. NO BARRIERS**
- 77. DON'T KNOW/NOT SURE
- 99. REFUSED
- QB2. If you were designing a system of mental health services for your community, what suggestion would you make, that would most help parents, who have a child dealing with a mental health crisis?

## [OPEN ENDED]



# **Section 4. Demographics**

QD1.	<ol> <li>Now I have just a few background questions and we'll be finished. How do you identify your listing.</li> </ol>	
	1. Male	
	2. Female, or	
	3. In another way – please specify, if you wish [SPECIFY]	
	9. PREFER NOT TO ANSWER	
QD2.	What is your current age?	
	[] [18-150]	
	999. REFUSED	
QD3.	Have you ever, in your lifetime, gone to see a health care professional for problems with emotions, nerves, or mental health?	
	1. Yes	
	2. No	
	7. DON'T KNOW/NOT SURE 9. REFUSED	
QD4.	Have you ever, in your lifetime, gone to see a healthcare professional for problems with your use of alcohol or drugs?	
	1. Yes	
	2. No	
	7. DON'T KNOW/NOT SURE 9. REFUSED	
QD5.	How many children do you have that are	
	a. Under age 3 in your household?	



	b. 3-12 years old in your nouseriold?			
	c. 13-19 years old in your household?			
	[NUMBER OF CHILDREN]			
	77. DON'T KNOW/NOT SURE			
	99. REFUSED			
QD6.	Are you the parent or legal guardian of this child/these children?			
	[INTERVIEWER NOTE: Include Foster and Step parents]			
	1. Yes [SKIP TO QD8]			
	2. No			
	7. DON'T KNOW/NOT SURE			
	9. REFUSED			
QD7.	How are you related to this child/these children?			
	11. Brother			
	12. Sister			
	13. Grandmother			
	14. Grandfather			
	15. Aunt			
	16. Uncle			
	17. Cousin			
	18. Other relative			
	19. Roomate, husband, wife, boy/girlfriend			
	20. Other [SPECIFY]			
	OO DEFLICED			
	99. REFUSED			
QD8.	Is the child/Are the children covered by health insurance?			
	1. Yes, for all children			



2. Yes, for some of the children

3. No [SKIP TO QD10]

7. DON'T KNOW/NOT SURE [SKIP TO QD10]

9. REFUSED

[SKIP TO QD10]

- QD9. Does it cover mental health services?
  - 1. Yes
  - 2. No
  - 7. DON'T KNOW/NOT SURE
  - 9. REFUSED
- QD10. What is the highest grade or level of school that you have completed?
  - 1. 8th grade or less
  - 2. Some high school (Grades 9 11), but did not graduate
  - 3. High school graduate (Grade 12) or GED
  - 4. Some college (1 3 years) or technical school
  - 5. 4-year college graduate
  - 6. More than 4-year college degree
  - 7. DON'T KNOW/NOT SURE
  - 9. REFUSED
- QD11. Which of the following best describes where you live? Do you live...
  - 11. On a farm,
  - 12. In a rural setting, not on a farm,
  - 13. In a rural subdivision outside of city limits,
  - 14. In a small town of less than 5,000 people,
  - 15. In a large town of 5,000 to less than 25,000 people,
  - 16. In a city of 25,000 to less than 50,000 people,
  - 17. In a city of 50,000 to less than 150,000 people, or
  - 18. In a city of 150,000 or more people?
  - 77. DON'T KNOW/NOT SURE
  - 99. REFUSED
- QD12. Are you currently...
  - 11. Employed for wages,



- 12. Self-employed,
- 13. Out of work for more than 1 year,
- 14. Out of work for less than 1 year,
- 15. A Homemaker,
- 16. A Student,
- 17. Retired, or
- 18. Unable to work?

### 99. REFUSED

- QD13. What is your annual gross household income from all sources before taxes? Is it...
  - 11. Less than \$15,000,
  - 12. \$15,000 to less than \$25,000,
  - 13. \$25,000 to less than \$35,000,
  - 14. \$35,000 to less than \$50,000,
  - 15. \$50,000 to less than \$75,000,
  - 16. \$75,000 to less than \$100,000,
  - 17. \$100,000 to less than \$150,000, or
  - 18. \$150,000 or more?
  - 77. DON'T KNOW/NOT SURE
  - 99. REFUSED

## [IF QD13 < 77, SKIP TO QD15]

- QD14. Can you tell me if your annual gross household income is less than, equal to, or greater than \$50,000?
  - 1. Less than \$50,000
  - 2. Equal to \$50,000
  - 3. More than \$50,000
  - 7. DON'T KNOW/NOT SURE
  - 9. REFUSED
- QD15. Are you of Hispanic, Latino, or Spanish origin?



- 1. Yes
- 2. No
- 7. DON'T KNOW/NOT SURE
- 9. REFUSED
- QD16. Which one or more of the following would you say is your race?

# [SELECT ALL THAT APPLY]

Would you say...

- 1. White,
- 2. Black or African American,
- 3. Asian,
- 4. Native Hawaiian or Other Pacific Islander,
- 5. American Indian or Alaska Native, OR
- 6. SOMETHING ELSE? [SPECIFY]
- 7. DON'T KNOW/NOT SURE
- 9. REFUSED

## [IF MORE THAN ONE RESPONSE TO QD16, CONTINUE. OTHERWISE GO TO QD18]

- QD17. Which one of these groups would you say BEST represents your race?
  - 1. White
  - 2. Black or African American
  - 3. Asian
  - 4. Native Hawaiian or Other Pacific Islander
  - 5. American Indian or Alaska Native
  - 6. SOMETHING ELSE [SPECIFY]
  - 7. DON'T KNOW/NOT SURE
  - 9. REFUSED
- QD18. What is your ZIP Code?



FRANCIS LAUER A YSS ORGANIZATION				
	77777 DON'T KNOW/NOT SURE 99999 REFUSED			
[NOTE:	IF TALKING TO RESPONDENT ON CELL PHO	NE, SKIP TO QD20]		
QD19. Do you have a cell phone or can you also be reached via cell phone?				
[Read o	only if necessary: Do you have a cell phone f	or personal or business use?]		
	1. Yes 2. No			
	7. DON'T KNOW/NOT SURE 9. REFUSED			
[NOTE: IF TALKING TO RESPONDENT ON LANDLINE, SKIP TO QD21]				
QD20.	. Does the house you live in also have a residential landline telephone?			
	1. Yes			
	2. No	[SKIP TO CLOSING]		
	7. DON'T KNOW/NOT SURE 9. REFUSED	[SKIP TO CLOSING] [SKIP TO CLOSING]		
[IFQ D19 or QD20>1, SKIP TO CLOSING]				
QD21.	. How many RESIDENTIAL LANDLINE telephone NUMBERS do you have in your home? Do not include cell phone numbers or fax numbers.			
	[ ] RESIDENTIAL PHONE LINES [1-10]			
	77. DON'T KNOW 99. REFUSED			
QD22.	Thinking about all the phone calls that you RECEIVE on your landline and cell phone, what percent, between 0 and 100, are received on your CELL PHONE?			
	Enter percent (1 to 100)			



888 Zero

777 DON'T KNOW/NOT SURE

999 REFUSED

## **CLOSING**

That's my last question. Everyone's answers will be combined to learn more about perceptions of children's health and emotional well-being in your community. I want to thank you for your time and cooperation today.

Good-bye.

# **COMMENTS / REMARKS**



### **Focus Group Methods**

A validation focus group was utilized following the telephone survey to crosscheck the findings from the telephone survey with themes from a focus group of parents from the same North Central Iowa area. One focus group was held in Charles City, IA in Floyd County in April 2017.

### Recruitment and data collection

A parent was eligible to participate in the focus group discussion if their child was twelve years old or younger, and they lived in one of seven North Central Iowa counties (that is, Cerro Gordo, Chickasaw, Floyd, Hancock, Mitchell, Winnebago, and Worth). Multiple methods were used to recruit focus group participants with varying degrees of success, including direct recruitment via telephone using both CSBR's research registry and the YSS telephone survey sample, flyers posted in local libraries and on the Facebook page of a Mothers of Preschoolers (MOPS) parent group, and snowball sampling. Most participants were recruited from the recruitment flyers and using snowball sampling among enrolled participants who shared information about the study with personal contacts who might also have been eligible.

One focus group with seven parents was conducted in Charles City (Floyd County) on April 10, 2017. Signed informed consent was obtained prior to the focus group as well as a demographic profile. Demographic questions included gender, race, and education level of the parent; and number and age of their child(ren). The session lasted 90 minutes in length and was moderated by Mary Losch, while Neal Pollock and Eva Aizpurua took field notes. The group discussions were audio-recorded and transcribed. Study protocol and informed consent process was approved by the Institutional Review Board at the University of Northern Iowa. Participants received a \$40 gift card per person to compensate them for their time.

### **Moderator Guide**

A moderator guide was developed echoing the contents of the questionnaire. The discussion focused on parents' perceptions of children's physical and mental health, and experiences with help-seeking.

Barriers to mental health treatment and suggestions for improvements were also discussed. See Table 8 for additional information on the discussion topics and Appendix C for the full moderator guide.

### **Analysis**

Inductive thematic analysis was used to identify major themes in the data that emerged from the content of the focus groups. CSBR staff who took notes at the focus groups carefully reviewed the transcripts and field notes to refamiliarize themselves with the discussion and to identify key themes that emerged. Content was then compared for each note taker to check for missing points to yield the key observations outlined in this report.



### **Participant Profile**

Table 9 summarizes the characteristics of the focus group participants.

Table 9. Demographic profile of focus group participants

Participant Number	Sex	Age group	Ethnicity	Highest Level of Education Completed	Number of Children Under 12	Number of Children Over 12
1	Female	35-42	White	Bachelor's degree	2	2
2	Female	35-42	White	Associate's degree	1	1
3	Female	18-34	Asian	Some college	4	0
4	Female	18-34	White	Associate's degree	1	0
5	Female	35-42	White	Associate's degree	2	1
6	Female	35-42	White	Graduate college or professional degree	3	0
7	Female	35-42	White	Graduate college or professional degree	4	0



### **Moderator Guide**

### [INTRODUCTIONS AND OVERVIEW OF PROCESS

### General concerns and knowledge about children's well-being

What, in your opinion, is the biggest challenge raising young children today?

When you think of physical well-being or physical health in young children, what comes to mind?

In general, how knowledgeable do you feel about your understanding of physical health in children as children grow?

When you think about mental health in young children, what comes to mind?

How knowledgeable do you feel about your understanding of mental health in children as children grow?

If you were to have questions or concerns about your child's mental health, where would you go for answers?

[Probe] Are there any specific people, organizations or agencies you would seek out or recommend to others if you or they needed information on children's mental health?

How easy or difficult would it be for you to find professional help?

[Probe]What makes it difficult/easy?

### Crisis identification and intervention

What circumstances or behaviors would you characterize as a "crisis" in a child?

What circumstances or behaviors would you characterize as a "mental health crisis" in a child?

If your child were to experience what you consider a mental health crisis, what do you think you would do to help stabilize the child's situation?

[Probe] What kind of help would you seek, if any?

In what ways do you think schools should assist children with mental health conditions, if at all? If you were providing advice or information to a friend or family member in your community about where to go for help with serious mental health issues in young children, what would you suggest?



### **Barriers to treatment**

What are the biggest fears or worries you think parents have when their child has a mental health condition?

What do you think are some possible barriers that would prevent you from seeking treatment for your child if diagnosed with a mental health condition?

If you were designing a system of mental health services for your community, what suggestion would you make, that would most help parents, who have a child dealing with a mental health crisis?

### Wrap up

What else is important that we haven't touched on related to this topic?



### ADULT: 30-Day Follow-Up Questionnaire (DRAFT JUNE 2017)

Check-In call	by provider – 30 days post discharge
Client Name:	Discharge Date:
Staff Name:_ measure	Survey Date: YSS Outcome
	Have the frequency of crises increased or decreased over the past 30 days? (Circle One YSS outcome measure  A. How many crises have occurred over the past 30 days?  Have you needed to seek additional crisis services in the last month?  Yes No (Circle One)  If so:
	A. What situation caused you to seek service? YSS outcome measure (trauma)
3	B. What service did you seek?  C. Was this service helpful? Yes No (Circle One)  B. Do you feel you are better able to help your child since receiving services from FLYS?  Definitely Somewhat Not Really (Circle One) YSS outcome measure  A. Have you been able to use the tools you received?  Definitely Somewhat Not Really (Circle One)  B. What skills or services do you feel would increase your ability to help your child
4	Has your child been able to attend school on a regular basis since being discharged?  Yes No (Circle One) External outcome measure (instructional minutes)  A. If no, what have been the obstacles to school attendance?
	Overall, how is your family today?



### YOUTH: 30-Day Follow-Up Questionnaire (DRAFT JUNE 2017)

t Name:_	Discharge Date:	
Name: sure	Survey Date: YSS or	utcom
5.	<ul> <li>Have you experienced any situations you felt were very bad/a crisis over the p month?</li> <li>Yes No (Circle One) YSS outcome measure</li> <li>B. If so: How many times and what were they like?</li> </ul>	ast
6.	<ul> <li>Did you seek any help for these situations in the last month?</li> <li>Yes No (Circle One)</li> <li>If so:</li> </ul>	
	D. What situation caused you to seek service? YSS outcome measure	
	E. What service did you seek ?	
	F. Was this service helpful? Yes No (Circle One)	
7.	. Do you feel you are better able manage your issues most of the time since rec services from FLYS? Definitely Somewhat Not Really (Circle On outcome measure	_
	A. Have you been able to use the tools you received?  Definitely Somewhat Not Really (Circle One)	
	Overall, how would you say you are doing today?	



### ADULT: 60-Day Follow-Up Questionnaire (DRAFT JUNE 2017) Check-In call by provider – 30 days post discharge Discharge Date:\_\_\_\_\_ Client Name:\_\_\_\_\_ Survey Date: \_\_\_\_\_ YSS Outcome Staff Name:\_\_\_\_\_ measure Thank you for taking the time to speak with us again. 8. Have the frequency of crises <u>increased</u> or <u>decreased</u> since we last spoke? (Circle One) YSS outcome measure C. How many crises have occurred over the past 30 days? \_\_\_\_\_ 9. Have you needed to seek additional crisis services in the last month? No (Circle One) Yes If so: G. What situation caused you to seek service? YSS outcome measure H. What service did you seek? I. Was this service helpful? Yes No (Circle One) 10. Do you feel you are better able to help your child since receiving services from FLYS? Definitely Somewhat Not Really (Circle One) YSS outcome measure A. Have you been able to use the tools you received? Definitely Somewhat Not Really (Circle One) C. What skills or services do you feel would increase your ability to help your child? 11. Has your child been able to attend school on a regular basis since being discharged? Yes No (Circle One) External outcome measure B. If no, what have been the obstacles to school attendance? 12. Overall, how is your family today?



How much do you agree or disagree with the following statements? (Please check one).

13.	Overall, I am very satisfied with the way Francis Lauer Youth Services (FLYS) provided services
	Strongly Disagree
	Somewhat Disagree
	Neither Agree or Disagree
	Somewhat Agree
	Strongly Agree
14.	Providers responded in a timely fashion.  Strongly Disagree
	Somewhat Disagree
	Neither Agree or Disagree
	Somewhat Agree
	Strongly Agree
15.	FLYS staff provided the support our family needed.  Strongly Disagree
	Somewhat Disagree
	Neither Agree or Disagree
	Somewhat Agree
	Strongly Agree
16.	FLYS staff made appropriate referrals to other services for our family.  Strongly Disagree
	Somewhat Disagree
	Neither Agree or Disagree
	Somewhat Agree
	Strongly Agree



17.	Overall, I am satisfied with the crisis and stabilization services provided.  Strongly Disagree
	Somewhat Disagree
	Neither Agree or Disagree
	Somewhat Agree
	Strongly Agree
18.	What is the likelihood of reaching out for additional services, if needed in the future?  (please check one)  Better, based upon services rendered  Same  Worse, based upon services rendered
19.	Considering your most recent experience, would you recommend this service to a friend or family? Please rank your answer on a scale from 1 to 10; 1 being not at all likely and 10 being extremely likely.  (Insert answer here)



### YOUTH: 60-Day Follow-Up Questionnaire (DRAFT JUNE 2017)

Check-In call by provider – 60 days post discharge Client Name:\_\_\_\_\_ Discharge Date:\_\_\_\_\_ Survey Date: YSS outcome Staff Name: measure 20. Have you experienced any situations you felt were very bad/a crisis since we spoke a month ago? Yes No (Circle One) YSS outcome measure D. If so: How many times and what were they like? \_\_\_\_\_ 21. Did you seek any help for these situations in the last month? No (Circle One) Yes If so: J. What which situation caused you to seek service? YSS outcome measure K. What service did you seek? L. Was this service helpful? Yes No (Circle One) 22. Do you feel you are better able manage your issues most of the time since receiving services from FLYS? Definitely Somewhat Not Really (Circle One) YSS outcome measure A. Have you been able to use the tools you received? Definitely Somewhat Not Really (Circle One) 23. Overall, how would you say you are doing today? How much do you agree or disagree with the following statements? (Please check one). 24. Overall, I believe Francis Lauer Youth Services (FLYS) staff tried their best to help me. Strongly Disagree Somewhat Disagree Neither Agree or Disagree Somewhat Agree Strongly Agree 25. FLYS staff provided the support that my family and I needed. Strongly Disagree



		Somewhat Disagree
		Neither Agree or Disagree
		Somewhat Agree
		Strongly Agree
26.	FLYS sta	aff linked me and my family up with other services. Strongly Disagree
		Somewhat Disagree
		Neither Agree or Disagree
		Somewhat Agree
		Strongly Agree
27.	Overall	, I am satisfied / feel good about the services FLYS provided. Strongly Disagree
		Somewhat Disagree
		Neither Agree or Disagree
		Somewhat Agree
		Strongly Agree
28.		the likelihood that you will reach out for additional services to FLYS or others, if in the future? (please check one)  Better, based upon my experience with FLYS
		Same
		Worse, based upon my experience with FLYS
29.	or fami	ering your most recent experience, would you recommend this service to a friend ly? Please rank your answer on a scale from 1 to 10; 1 being not at all likely and g extremely likely (Insert answer here)



## YOUTH AND SHELTER SERVICES, INC. CHILDREN'S MENTAL HEALTH CRISIS PLANNING WORK GROUP FRANCIS LAUER - A YSS ORGANIZATION

Date	Participant Name (Please Print)	Participant Signature	Agency	Last 4 Digits SS #	Time In	Time Out
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## YOUTH AND SHELTER SERVICES, INC. CHILDREN'S MENTAL HEALTH CRISIS PLANNING WORK GROUP FRANCIS LAUER – A YSS ORGANIZATION JANUARY 19, 2017 – NHA PARENT SUPPORT FOCUS GROUP

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### CHILDREN'S MENTAL HEALTH CRISIS PLANNING WORK GROUP FRANCIS LAUER - A YSS ORGANIZATION YOUTH AND SHELTER SERVICES, INC. BOARD ROOM-MARCH 2, 2017

### PARTICIPANT ATTENDANCE

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## YOUTH AND SHELTER SERVICES, INC. CHILDREN'S MENTAL HEALTH CRISIS PLANNING WORK GROUP FRANCIS LAUER – A YSS ORGANIZATION BOARD ROOM – MARCH 20, 2017

### PARTICIPANT ATTENDANCE

2:00 PM-4:00 PM

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## YOUTH AND SHELTER SERVICES, INC. CHILDREN'S MENTAL HEALTH CRISIS PLANNING WORK GROUP FRANCIS LAUER – A YSS ORGANIZATION BOARD ROOM – APRIL 10, 2017

### PARTICIPANT ATTENDANCE

2:00 PM-4:00 PM

		PARTICIPANT AT LENDANCE	SINDAINCE			
Date Participant Name (Please Print)	Please Print)	Participant Signature	Agency	Last 4 Digits SS #	Time In	Time Out
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## YOUTH AND SHELTER SERVICES, INC. CHILDREN'S MENTAL HEALTH CRISIS PLANNING WORK GROUP FRANCIS LAUER - A YSS ORGANIZATION BOARD ROOM - MAY 3, 2017 1:00 PM - 3:00 PM

### PARTICIPANT ATTENDANCE

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## YOUTH AND SHELTER SERVICES, INC. CHILDREN'S MENTAL HEALTH CRISIS PLANNING WORK GROUP FRANCIS LAUER - A YSS ORGANIZATION BOARD ROOM - JUNE 8, 2017 1:00 pm - 3:00 pm

### PARTICIPANT ATTENDANCE

Date	Participant Name (Please Print)	Participant Signature	Agency	Last 4 Digits SS #	Time In	Time Out
6/8/17	Bright Christian an	Bugal Churchyn	Priv. Prac	3710	(0:	4:00
481	Sound Knudson	Saluhlum	APP	8595	12:00	3:00
1/6/17	Juston Hayland		255	2057	(,00	4:00
1/8/1	6/8/17 Alice Ciavarelli	Minasoulli	YTF	2535	1:00	3:00
1/8/9	6/8/17 ENS A. Gonzalez		CSBR	4834	9:30/10	30/10 3:00
(48/1)	Next Pollock	most	CSBR	o333	9.30/100	3:00
6/8/0	Sally Dursanberg	Jally Duosenby	OKAN	815.31	12.00	2:00
4/8/17	Bob Lincoln	No.	553	2843	20.	4:00
6/8/17	May Schissel	Mary Share	MB Course Stu	16291	1:00	5,500
18/21	Menica Paulsen	7 ha Pake	Bliess C	2300	9:30	3:00
6/8/17	Mary Losse	May Exerce	UNI CSOR	83.17	9:307	3:00
11.8.0	Sadie Mayor	Rudiu muzz	MCCSO	8000	12:00	3:00
1.8.0	6.8, Mayoun McAleek (	Jon Male	ELYS/ YES	0509	1:00	3:00



# YOUTH AND SHELTER SERVICES, INC. CHILDREN'S MENTAL HEALTH CRISIS PLANNING WORK GROUP FRANCIS LAUER – A YSS ORGANIZATION BOARD ROOM – JUNE 22, 2017

### PARTICIPANT ATTENDANCE

11:00 AM - 3:00 PM

VSS VSS	622	6-22	4.22	4.22	6/20	6/22	6/22	6/22	400	6/22	6/2	Celin	922	Date
Sun Sy OLSON DISTANCE	Brigid Christianson	Bub Lincoln	Sally Duesenberg	JAMIC Meyor	Jean M. Hove	Jasen Hagland	Eva Aizpurus	Alice Ciavarelli	Mary Shissel	Monita Paulsen	May Losa	Caral Senson	STATE KNIKISSE	Participant Name (Please Print)
Mar W	Brighol Chardman	Jest Second	Gally Dussender	Gadi My	mean		A 13	and assalli	Many Schinson	Mon Pal	Way & Jose	Caral Sensor	Sum ha	Participant Signature
RHD	P.P	SSO	O 6265D	muso	YS/FU	584	CN-	YTE	Consulting	CSS	UW/	A6A	ADA	Agency
5319	3710	38436	8169	8020	0509	7082	H198	2235	6291	2300	8517	3627	9558	Last 4 Digits SS #
S. S.	12:30	12:15	12:00	10:00	1000	11:00	10:00	10:00	100:00	11:00	10:00	10:00	(0:0)	Time In
2.18 2.00	2:00	2:00	2:00	2:00	2:00	2:00	10:00 2:00	11.00 -2.00	→ 1.00 → 1.00	1 2:00	10:00 2:00	2:00	2:00	Time Out





## YOUTH AND SHELTER SERVICES, INC. CHILDREN'S MENTAL HEALTH CRISIS PLANNING WORK GROUP FRANCIS LAUER - A YSS ORGANIZATION BOARD ROOM - JULY 10, 2017

### PARTICIPANT ATTENDANCE

10:00 AM-1:00 PM

1.10.17	7/10/17	C//0//1	7/18/19	4/01/1	FID1/F	1/10/17	7/10/15	Liloit	Date
7.16.17 JAdic Mayer	Thinh Alice Cavarelli	1/10/17 Monica Paulsen	Waln Jean MCHARL	Brigid Christianson Bughd Christianian Priv Prac	FIIOIT END AUDIONS	Mol17 Neal Hollack	May Schusse	Mary leach	Participant Name (Please Print)
Gudu Mayer	alu Cararlle MCYTF	Il la Pak	Dem Mcall	Bughd Christman	A A A	WW.	May & Missin	May E. Luxa	Participant Signature
MCCSO	MCYTE	CSS	FLYS	Phil Prac	CNI	IND	M. Consult	LIMI	Agency
0110	2235	2300	0509	3710	1988	0333	6291	8317	Last 4 Digits SS #
10:15	10:05	16.00	10:0)	10:00	(0:00	10:00	10:00	10:00	Time In
12:00	10:05 12:00	12:00	12:00	10:00 12:00	12:00	12:00	12:00	12:00	Time Out